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ABSTRACT

This conference report presents research strategies and ethical considerations concerning consumer participation in the health care process. Section 1, background, lists the beginnings of self-care in health, the programs that have sprung up, and their supporting organizations, and the medical tasks performed by the consumers in those programs. Section 2, proceedings, defines consumer self-care, explains research strategy, topics and particulars, and ethical considerations. The summary of recommendations proposes four areas of research: (1) the parameters of self-care (short-term research is suggested), (2) consumer-oriented research (a national survey is recommended which would be supplemented by a review of literature on consumers coping), (3) health care provider research (the role of the provider, the assessment of him, and a review of his education, and (4) demonstrations (the settings and populations are described). (Appended are four papers dealing with the concept of caring in the self-care movement, an international perspective of self-care, the health beliefs of the U.S. population, and research and demonstration issues in self-care. The paper on research and demonstration includes 146 references.) (VB)

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NCHSR

RESEARCH PROCEEDINGS SERIES

Consumer Self-care in Health

August 1977

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
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Abstract

Consumer self-care in health is a growing movement wherein lay persons increasingly function for themselves to prevent, detect, and treat health problems, and promote good health in a manner which supplements or substitutes for professional services. The movement can be traced to social and health legislation of the 1960s, changes in nursing theory, and the growth of self-help groups (also, the more recent Feminist movement, as well as the growth of women's centers and feminist therapy collectives have been influential to the popularization of self-care in health). The conferees have recommended a broad range of new research on the topics of a survey of consumer and health care provider attitudes and practices regarding more consumer involvement in the health care process; and the demonstration of new self-care theory and the evaluation of existing self-care programs and theory in terms of costs, efficiency, and satisfaction. The conferees also discussed ethical issues regarding research risks, the quality of self-care, and "at-risk" populations. Appended are four papers describing existing programs, the history and logic of the movement, and inferences concerning the consumer's desire for increased self-care.

Acknowledgements

ii The conference was organized by John D. Gallicchio, Research Psychologist of the NCHSR Division of Health Services Research and Analysis, who also prepared this report. Harvey Dohn Rushing of the Division provided administrative support to the conference. George A. Silver, M.D., of the Yale University School of Medicine, was the Conference Chairman. Group Leaders were Jerry Weston, Sc.D., and Robert M. Thorner, Ph.D., of NCHSR. Rapporteurs were Kathleen Ittig, Ph.D., and James R. Ullom, NCHSR; Lee B. Sechrest, Ph.D., Florida State University; and Eva J. Salber, M.D., Duke University Medical Center. Presentations were made by Dr. Silver; Gretchen V. Fleming and Ronald M. Andersen, Ph.D., both of The University of Chicago; Lawrence W. Green, Ph.D., The Johns Hopkins University; and Lowell Levin, Ed. D., Yale University. Early conceptual planning was contributed by Sherman R. Williams, The Johns Hopkins University.

Foreword

The National Center for Health Services Research (NCHSR) has an innate interest in the quality of interaction between the citizen and the Nation's health resources. Research on innovative health care historically has focused on the professional health care provider to the exclusion of significant lay participation in the process of delivering care. Any complete review of the process must necessarily include the consumer's role. The NCHSR research conference on self-care was convened to formulate the research issues inherent in the self-care movement, and to further understanding of the Nation's research needs regarding consumer participation in the health care process. The attendees responded by posing incisive research questions as well as by addressing leading ethical issues involving the responsibilities for high quality health care and identifying the best interests of the consumer. Although the group was not large, it provided representation for problems of national scope and the attendees offered a wide-range diversity of opinion. This conference report is an effort to reflect those opinions as faithfully as possible.

Gerald Rosenthal, Ph.D.
Director
National Center for Health Services Research
August 1977

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Background

The National Center for Health Services Research (NCHSR) regularly calls upon consumers, policymakers, health care providers, and members of the research community to engage in critical discussions of research needs and strategy. This document is an NCHSR staff report on research issues and recommendations of a conference on the growing consumer self-care movement in health.

The conferees were faced with the task of isolating research strategies needed to answer important questions about the efficacy of consumer self-care activities. Self-care is very much a social issue rather than a technology, and therefore does not lend itself easily to quantifiable research approaches. That state of affairs is reflected in the report's emphasis on ethical issues, and in the generality of its recommendations. The task is to apply objectivity, internal validity of design, and generalizability to future research activities on this issue.

The beginnings of consumer self-care in health may be traced to initiatives such as community action started under the Economic Opportunity Act of 1964, and to consumer participation encouraged by legislation establishing the Regional Medical Programs in 1965. The beginnings also may be traced to the development of changes in nursing theory encouraging self-care, and the development and popularization of group dynamics and programs utilizing behavior modification techniques addressed to such problems as weight loss and smoking.[1]

But other antecedents are involved which are not related to legislation, group membership, or patient role. The popularity of the Nader movement, the questioning of corporate motives and products, and revelations in Federal government are precipitating a philosophy of consumer watchfulness and activation. Most changes probably are occurring among middle income groups, who are growing aware of options within numerous processes that affect them.

Recent problems with inflation and energy supplies have fostered a growing attitude that consumers must now attempt to conserve a wide range of resources to avert economic and physical destruction, both on personal and national levels. The feeling has caused a national uneasiness or concern regarding the *manageability* of resources and inflationary processes. This concern can extend to health attitudes and personal health management, and may not be related to attitudes toward personal physicians and the quality of care they deliver to the individual.

During the month of July 1976, Barnes and Noble, New York, noted record sales of publications of the do-it-yourself variety, and health topics were among the five best sellers. Author-physicians such as Sehnert, Vickery and Fries, and Samuels and Bennett have written consumer health guides that have been very well received by the public. Such sensitivity to the consumer sector's needs also is beginning to extend into medical education. For example, the University of California School of Medicine (San Francisco) has a graduate program in Health Psychology which aims to adapt the delivery of health care to consumer needs and capabilities. Also, a number of agencies in the U.S. Public Health Service are engaged in a cooperative program to develop a curriculum of patient education skills addressed to physicians in primary care residencies, and especially family practices. Among other things, the program is interested in teaching physicians to assess patient competency to perform medical tasks as well as to consider delegating certain tasks to the patient.

In 1975, staff of the National Center for Health Services Research met with a staff member of the Office of the Assistant Secretary for Planning and Evaluation/Health to discuss the survey of a sample of self-care programs. The Office of the Assistant Secretary was already supporting a contract to survey health education programs, and NCHSR suggested providing additional resources to increase the survey's attention to programs which had a self-care orientation.

The survey revealed programs that were characteristically new, lacked in-depth evaluations, and addressed a wide variety of health problems.[2] These programs were sponsored by university centers for continuing education, cooperative exten-

[1] Green, Lawrence W., *et al*, "Research and Demonstration Issues in Self-care: Measuring the Decline of Medicocentrism". See *Appendix D* (March 1976).

[2] Arthur D. Little, Inc., *A Survey of Consumer Health Education Programs*, report to DHEW (National Technical Information Service, Springfield, VA, 3 volumes, order numbers PB 251 773, PB 251 774, PB 251 775), 107–156.

sions, regional medical programs, health maintenance organizations, educational centers for categories of disease such as diabetes, free standing clinics, local health departments, mutual aid groups such as parents groups involved with the sudden infant death syndrome (SIDS), and the Ostomy Society.

Examples are as follows: [3]

The course for the activated patient at Georgetown University teaches consumers to use the health system, understand preventive medicine, and perform self-care tasks such as the taking of blood pressure, use of the stethoscope, measuring body temperature, first aid, injection, and diagnosis.

The Columbia Medical Plan Throat Culture Program in Columbia, Maryland, teaches parents to obtain throat cultures from their children.

The Free-standing Health Center in Boston provides a broad range of self-help education to women on topics such as self-examination and gynecology.

The Group Health Cooperative of Puget Sound addresses self-care of both diabetes and hypertension.

The Regional Self-help Medical Care Training Project (RMP at Salt Lake City, Utah) provides self-care education to rural residents on a broad range of preventive practices, simple medical procedures, and diagnoses.

The Reston-Georgetown Medical Center offered a 10-week course in 1975 to introduce participants to medical decision-making through the use of protocols for 65 common complaints.

The University of Arizona's Cooperative Extension Service offers self-care education to rural residents, in order to reduce their "risk age" through behavior change.

The following list of medical tasks performed by consumers in these programs is limited, but many tasks address a number of health problems with multiple effects. [4]

1. Diagnosis of common conditions
2. Insulin injection
3. Urine testing
4. Breast self-examination
5. Cervical self-examination
6. First aid tasks
7. The taking of blood pressure
8. Obtaining throat cultures
9. Hyposensitization injections
10. Ear wax irrigation
11. Kidney dialysis
12. Physical therapy for arthritis

(Note that the list includes only tasks that are normally performed by a health care provider and does not address many preventive and maintenance tasks, though they too are addressed in the surveyed programs).

The NCHSR Research Conference on Consumer Self-care in Health was held at the Dulles Marriott Hotel, Reston, Virginia, on March 24, 25, and 26, 1976. The conference was chaired by George A. Silver, M.D., Yale University School of Medicine. Although the group was relatively small, this conference reportedly was the first national level meeting on the topic.[5] The conferees were charged with addressing the need for research, the nature of such research, and the outcomes that might be expected from organized self-care activities.

Several papers were presented early in the meeting (see Appendices):

A. "The 'Care' in Self-care," George A. Silver, M.D., Yale University.
B. "Self-care: An International Perspective," Lowell S. Levin, Ed.D., Yale University.
C. "Health Beliefs of the U.S. Population: Implications for Self-care," Gretchen Voorhis Fleming and Ronald Andersen, Ph.D., The University of Chicago.
D. "Research and Demonstration Issues in Self-care: Measuring the Decline of Medicocentrism," Lawrence W. Green, Dr. P.H., The Johns Hopkins University; Stanley H. Werlin and Helen H. Schauffler, Arthur D. Little, Inc., and Charles H. Avery, M.D., University of California.

After the papers, the meeting divided into two groups of approximately 15 persons each, for simultaneous discussion of the topics. During the last three hours of the conference, the members met in plenary session to compare recommendations. The main purpose in dividing the group during the work session was to reduce the numbers in a group, aid in controlling discussion, and to facilitate individual participation. The groups were moderated by Robert Thorner, Ph.D., and Jerry Weston, Sc.D., of NCHSR.

The structure of the conference was a vehicle for addressing the self-care issue, and is not reflected in the format of this report. This document is an NCHSR staff report that attempts to summarize the major themes discussed, and is not an official report of the conferees.

[3, 4] Ibid

[5] In 1975, Switzerland and Copenhagen were sites of international meetings.

Definition

The process of defining consumer self-care revealed that the attendees tended to view the American consumer as one who was not receiving enough information to attain a level of health consistent with the Nation's cultural and technological capacity. Self-care was considered a potential resource for improving the general quality of life, but not a process that should be allowed to shift attention away from an inefficient health services delivery system or to shift blame for such inefficiencies from the health care provider totally to the consumer.

A distinction was made between traditional health education and the self-care education model: self-care focuses on the active consumer and his interaction with the health care system, while traditional health education appears to be more professionally oriented. In the former, control of the nature of consumer interaction with the health care system and the progression of health care problems is more in the hands of the consumer. Also, self-care education, in its relatively brief history, has tended to use more nontraditional educational methods that differ in content and/or mode of delivery. It was stated that self-care education is more life-style oriented than content oriented. Actually, traditional health education theorists might argue that the latter distinction is minimal; certainly Irwin Rosenstock puts considerable emphasis on life style in his "Health Belief" model of health behavior. The traditional theorist might concede, though, that the success of a comprehensive program of consumer self-care (by whatever measures) is more dependent upon certain life-style variables than adherence to a regimen of care prescribed by health education content.

If the conferees showed general agreement in tone regarding the positive potential of self-care, there was a subtle polarity of the group regarding the locus of control of the self-care program. This revealed itself as a slight disagreement over where the ultimate responsibility for health care activity rests: with the consumer or with the health care professional. Perhaps the question should be conceived as research to determine which control provides better motivation, more satisfaction and efficiency, and better health.

Primary care was considered to be a major target of self-care processes. But there was some disagreement as to whether primary care is an area that the professional health care provider is willing to concede to self-care. One member said that the profession may not want to give up any of its "turf," and a reply was that primary care contains a large number of areas the profession is perfectly willing to give up. Another participant stated that the profession can be expected to challenge those portions of the self-care movement that relate to specific tasks performed by consumers—yet other tasks can be predicted to be turned over willingly to the movement. There followed some discussion about the real need to polarize self-care activists and the medical profession: the fact is that most professionals probably provide some degree of self-care education for their patients, and that research's approach to addressing self-care and the health profession should be to look at that end of the continuum, such as Dr. Donnell Etzwiler [1] in Minneapolis and those who are emphasizing the activated patient. It was further noted that at an international symposium on the role of the individual in primary health care (Copenhagen, August 1975), a similar polarity existed. Proponents occupied positions on a spectrum ranging from the attitude that there were *some* health care activities the consumer might assume, to the more extreme Illichian [2] view that consumer activities have more or less sole legitimacy in the care process.

The group felt that any definition of the self-care process should address the goal of enhancing the ability of lay persons to make decisions regarding their health care and also to be able to recognize and exercise options of care. These options

[1] Donnell D. Etzwiler, M.D., Diabetes Education Center; Pediatrician, St. Louis Park Medical Center, Minneapolis, Minnesota. He has studied a contractual relationship between the physician and his client.

[2] Ivan Illich, *Medical Nemesis: The Expropriation of Health* (Pantheon, New York, 1976).

should range from the use of the traditional medical care model to activities supplementing professional care, as well as to activities that substitute for professional care. It was generally agreed that such care should relate also to those who are close to the subject.

Discussion also centered around distinctions between the concept, "self-care" and the similarly popular concept of "self-help." There was concern that the former term does not adequately imply "mutuality," or people aiding one another, but rather emphasizes strictly personal health care. Another view was that the term "self-help" was not quite adequate for the group's use, as it carried connotations of organized consumers, such as Alcoholics Anonymous, with common problems. In general, no real momentum was built up to drop the term "self-care" in favor of "self-help," but it was agreed that the conferees would treat the two terms as very nearly identical.

One of the first moves toward formulating an acceptable working definition was a proposal to label self-care as "the substitution of activities normally carried out by a physician." The group generally felt that the definition should be considerably broader, with at least an implication of new kinds of health care provider/consumer interactions. But other dimensions also deserved to be addressed by the definition: (a) the degree of initiative on the part of the consumer in recognizing health care needs and taking action, (b) the degree of utilization of traditional medical services, (c) whether care is directed toward the self or expanded in scope to include others, and (d) the degree of adherence to a medical model. It was proposed that the definition address all health care consumers rather than limit itself to the patient. Implicit in this is the need for self-care activities to address preventive care as well as the maintenance of chronic and episodic health problems. The latter includes crisis health problems.

In characterizing the knowledge required and the activities that the consumer might undertake, some interesting terminology appeared. The terms "substitutionary", "supplementary", and "additional" addressed the position of self-care activities in relation to traditional health services delivery. Substitution lies at one end of the spectrum, with the consumer substituting his care for that of the professional's. Supplementation would lie somewhere in the middle of the spectrum, with the consumer providing care that is meant to be supportive of professional care (or conversely, where a consumer self-care regimen is supplemented by a professional's care as needed). Note that supplementary care implies the possibility of incomplete professional care, so designed to accomodate lay input. At the far end of the spectrum lies that care provided in addition to professional care. Such care carries implications of working in concert with professional care that is considered complete. It was recommended that the adopted definition contain an element of substitution, at the least.

As put forth, the definition is:

> Self-care and self-help are parts of a matrix in the health care process whereby lay persons can actively function for themselves and/or others to (1) prevent, detect, or treat disease, and (2) promote health so as to supplement or substitute for other resources.

The key elements of the definition are that self-care deals with the well consumer and the sick patient, and that self-care may occupy a place in a spectrum, from the consumer being co-responsible for a treatment regimen to the provider being uninvolved in that regimen.

Research strategy

The research needs and methodologies that are indicated for self-care are not necessarily self-evident. It has not been easy to evaluate the effects of most forms of medical care, and the conferees expect that self-care will prove no easier.

The early implementation of a research program is essential, as self-care projects and materials are being rapidly proliferated. It was suggested by the group that NCHSR support short-term research on the topic, as opposed to an emphasis on longitudinal studies which feature relatively "fixed" independent variables. Since the self-care movement is relatively young, there is a lack of established theory and method, and short term research efforts may provide findings which can assist the movement to achieve a maximum efficiency. The payoffs of longitudinal studies, on the other hand, could be expected to be outweighed by the time lost in generating findings. This suggested short-term agenda should address research which contains an element of substitution: the lay person providing care which is traditionally supplied by professional medical personnel.

It was stated that the ultimate objective of a program of research should be to assess the effects of self-care activities upon consumer health and general well-being. But it was suggested that researchers take a liberal approach to the nature of the effects in question. Consumer satisfaction, consumer effectiveness or competency in illness situations, and the containment of health care costs are examples of outcome measures which should be given strong credence. Changes in knowledge of educational content should be desirable only as intermediate outcomes.

However, the group was divided on the recommended approach to supporting research objectives. The question was centered on whether to emphasize demonstration/project evaluation efforts or baseline data and analyses on the current extent of self-care practice in the United States.

Suggestions were made for demonstrations of various models of self-care. These should be established in settings such as: prepaid group practices, family practices, multiple specialty clinics, emergency medical services settings, public schools, youth service organizations such as the 4-H, and a limited number of chronic care or long-term care settings. NCHSR was warned to be cautious and selective in the early programming of demonstrations, since, for example, disease-specific health care education programs appear to be more methodologically advanced compared to more comprehensive programs, and NCHSR may be able to capitalize on knowledge gained in some of the categorical disease areas.

Many attendees stated that considerable baseline survey information is necessary before plausible models can be developed which are worthy of demonstration. However, not all conferees agreed that baseline survey efforts should postpone implementing demonstrations. A number of self-care education proponents believe they have isolated efficacious treatments which need only to be fully proven in the field. But the conferees generally agreed on the importance of baseline studies. Such information should be gathered as both an "intelligence network" of self-care projects and a national social survey to document the extent of self-care activities in the United States. An example of the need for such baseline information was that new health care manpower needs and configurations in self-care will remain undetermined until we first learn about the health behavior of the population of the United States. In gathering such data some considered it important to avoid national samples because they might pose difficulties in relating the individual to the particular system of medical care which he uses. Instead, community-based or Health Systems Agency (HSA)-based samples were considered preferable. Others voiced the opinion that a national sample could address individual systems of care when properly drawn and stratified.

In pushing for resolution, the Chairman stated his understanding that the group recommends that NCHSR support demonstration activities, although more national survey data are necessary. The survey needs are probably the most critical element of the two, but acceptable evaluation of existing program models requires a degree of demonstration. It was agreed that caution is indicated in committing relatively large quantities of resources to demonstration, until national survey findings can support sound models for demonstration.

Children and the elderly were recommended as populations that may be most in need of self-care education, or may be able to show the most gains within a number of "outcome" parameters. It was further suggested that research be carried out on the effects of introducing self-care coursework into public school curricula, especially in the lower grades.

It was suggested that a significant amount of self-care research should be formulated to address the family unit and the school system . . . take advantage of what is currently known about mores and human development. The concept of such self-care education was preferred to be comprehensive in nature rather than geared to address categorical health problems. It was suggested that such comprehensive self-care treatment could be measured against, for example, health services utilization patterns and levels, hospitalization, disability days, mortality, and morbidity rates. Primary care in general was considered an excellent subject for research.

The value of consumer education and evaluation activities carried out under categorical disease programs was not discounted. Pioneering efforts for assigning consumers participative roles in the care process have come from programs that have addressed categories of diseases such as diabetes and kidney disease; these programs have often produced useful evaluation methods and findings as well. In discussing the value of categorical disease programs in contributing to a body of self-care research, it was suggested that relative difficulties of specific self-care tasks needed to be assessed and that many categorical programs already have data on tasks consumers can and cannot execute safely. Diabetes was a case in point; in the process of self-injection of insulin, the diabetic has assumed a task normally carried out by a professional. If an assessment of difficulty could be carried out on a large number of similar tasks, then "candidate" tasks could be isolated for demonstration in controlled settings.

Finally, a strong strategy recommendation was that a portion of self-care research should focus on the professional and the changed role he may assume in any new system of health containing self-care orientation. One way of altering the professional's "set" in relating to the consumer/patient is to introduce curricula early in the former's professional training that emphasizes aspects of the patient-professional relationship. It is believed that such material is currently presented in inadequate quantities and too late in the professional's training process to be effective.

Research topics and particulars

The conferees' recommendations were to establish hypotheses about the efficacy of a defined set of self-care activities and projects, and to demonstrate efficacy along economic, care quality, and attitudinal parameters. Demonstrations of models of self-care programs may be classified for example, by their distance from the "medicocentric" point, as described by Green (see appendix D). Design of these models should be based upon assessments

of consumer and provider attitudes and behavior regarding self-care.

As part of assessing efficacy, it was suggested that a portion of self-care research should aim to determine the limits of consumer competency in performing various medical procedures. It was suggested that such competency is a function of "task difficulty." But task difficulty is only one dimension of the problem. The objective is to array or generate a taxonomy of all tasks that are amenable to self-care, determine what population groups show most success with specific tasks, and determine what conditions are antecedents of success. It was suggested that tasks could then be assigned "probabilities" that they might be successfully performed by specific categories of consumers. Tasks could be assigned probabilities ranging in difficulty from, for example, care of the feet to tonometry. Once difficulty levels are known, better prescription and a degree of "eliminating the middleman" can be achieved.

According to the conferees, a survey effort is required to generate an array of tasks, relate these tasks to categories of consumers, and further isolate numerous conditions under which such tasks are now being carried out by Americans. Three categories of data would be collected in such a survey: (1) population characteristics such as income, ethnicity, education level, access to services, and the configuration of available services; (2) data regarding the sample's incidence of health problems, responses to those problems, and self-care tasks commonly undertaken; and (3) data on consumer attitudes, perceived needs, and acceptability of self-care activities. Such a survey should begin to reveal the current level of individual self-care being carried out by the population, as well as the potential for increasing that level. Essentially, it would be a large scale descriptive study of consumer health behavior. It was generally agreed that the study could provide a data base for experimental intervention. (An issue that may not have been adequately covered was the determination of the real efficacy of self-care behaviors to be surveyed, as compared to traditional medical treatments. The need for a clinical follow-up was briefly addressed, but not in depth. The relating of difficulty levels to self-care tasks would apparently require some type of validation procedure. Validating data could perhaps be collected either as part of the survey or during the process of carrying out experimental interventions using the survey as a data base.)

As stated earlier in this report, a number of conferees were concerned that a national sample would be unable to relate individuals to available systems of care, and they therefore recommended that the survey (or surveys) be regionally or even community-based. Others felt that a national sample could be appropriate when properly drawn and stratified.

Related to the consumer behavior survey was a recommendation that NCHSR support an extensive survey of self-care projects, both provider-initiated and consumer-initiated. The study by Lawrence Green prepared for the Conference was cited as an excellent example (appendix D); what is now needed is a broadening of the scope of projects to be addressed.

It was recommended that NCHSR collect data on the attitudes of physicians and other health care providers toward teaching self-care techniques to patients. The survey should include gathering data on provider behavior, i.e., what the provider actually does about encouraging consumer-initiated treatment.

Although the conferees agreed on the value of primary data, it was recommended that NCHSR not overlook data already collected from other studies, under labels other than self-care. For example, Mary Ann Lewis of UCLA has closely studied childhood health and health behavior. Charles E. Lewis is the principal investigator of the NCHSR-supported Health Services Research Center at UCLA, which studies problems related to the health and illness behavior of patients and consumers. Also, the National Institute of Mental Health has supported numerous studies on coping behavior and conflict resolution. Green and Becker have done a review of the literature on the family approach to compliance with medical regimen, reported in *International Journal of Health Education* (1975); Lois Pratt has authored several pieces on the family and health care, and a review of research entitled, "The Significance of the Family in Medication," *Journal of Comparative Family Studies*, 4 (Spring 1973). But the conferees' emphasis on reviews of literature was a qualified one. One member stated that he would ". . .hate to see the Center spend their money that way. Any researcher worth his salt, before he does a secondary analysis, will do a review of the literature. . ." the NCHSR might, however, execute a "small personal services contract" with someone who has a good overview of the literature on behavior and unattended illness.

Examples of other potential sources of data were: The American Academy of Family Practice, the American Academy of Pediatrics, the Group Health Association of America, the American Association of Community Colleges, and various Self-healing Workshops in the San Francisco Bay area.

Adults who are currently involved in the health care system, such as enrollees in health maintenance organizations, were considered prime targets for research. Also, local health departments and social service settings were considered important, to the extent that they have active outreach services. In general, highly organized health care settings and enrolled or otherwise specified populations were recommended partly because of

hypothesized benefit to the consumer and partly because of the "controlled environment" they employ. The school and health care organization settings allow for controlled introduction of self-care treatment as well as valid measurement of outcome variables such as cost of care, quality of life, and consumer satisfaction. Further, there was a general feeling that self-care could be most useful when employed in concert with organized health care delivery systems. The measures of system efficiency and the data that health care organizations collect would be useful tools in self-care research, as the ultimate goals of health care organizations should be nearly the same as consumer self-care.

Rural residents and the elderly, as special populations, were considered important but remained somewhat unspecified regarding a research plan. The two groups merit special caution as, in the case of rural experimentation, it was generally agreed that self-care should not be looked upon by policy makers as an easy solution to the geographical scarcity of services. In the case of the elderly, their vulnerable condition makes it essential that adequate options for health care be available to them at all times as part of research and demonstration undertaking. This is not to say, of course, that self-care intervention should not be attempted when no other options for care are possible.

Ethical considerations

Early in the conference, the attendees demonstrated a sensitivity to risks that may be involved in self-care research. It was stated repeatedly that self-care treatment must be used with caution in addressing the disadvantaged as subjects; the self-care concept—as a research issue—must be targeted not only to the disenfranchised, but should be addressed to the entire spectrum of consumers. It was further suggested that *initial* research on the topic should *not* be carried out on people considered "experimental by virtue of their social condition."

The view was voiced that self-care must not be looked upon as a "second best" form of medical care, but a proper sense of research objectivity would dictate that it should be experimentally tried among people who have available resources and options of medical care, i.e., middle and upper income groups, for example. These options should include more traditional forms of medical care.

In general, traditional forms of medical care were not disparaged. It was stated that self-care research should be conducted in the spirit of assuming that the current medical system delivers high quality care. It was also stated that the self-care movement cannot be used as a vehicle to shift blame to consumers for problems in the traditional health care delivery system.

Other ethical concerns were offered as a matter of record, and can probably be generalized to many forms of social research—forms of research and ethical considerations which the Department of Health, Education, and Welfare has dealt with for years.[3] For example, it was suggested that NCHSR support research designs which randomize subject assignment to treatment only *after* the subjects' acceptance has been obtained. Also, research risks should be considered. The risk/benefit ratio of any research project should be 1.0 or less, and in cases where potential risks are unknown, subjects should be so informed. Informed consent procedures for such research should contain an estimate of risk relative to conventional medical care.

Finally, it was suggested that we not construct a self-care system that leads to exploitation of women as practitioners of self-care.

[3] *Institutional Guide to DHEW Policy on Protection of Human Subjects*, DHEW Publication No. (NIH) 72-102 (National Institutes of Health, Division of Research Grants, Bethesda, Maryland 20014).

Summary of recommendations

Recommendations for research are addressed to the health services research and the behavioral research communities as well as to the National Center for Health Services Research. In general, the recommended research involves studies concerning health care providers, consumers of health care, and the formulation and demonstration of self-care theory.

1. The parameters

Research is needed on self-care education that is predominantly comprehensive in nature, and addresses primary care medical tasks. An emphasis on short-term research is suggested. Such research should contain an element of substitution (see "definition" section).

Dependent variables for such research should go beyond mere changes in consumer knowledge, but should address changes in, for example, consumer confidence and attitudes, health care utilization patterns, demonstrated health care skills, health care costs, hospitalization rates, and morbidity and mortality rates. For research supported by NCHSR, special emphasis should be placed on valid research designs using objective data, reliable data-gathering instruments and methods, and providing a high degree of control.

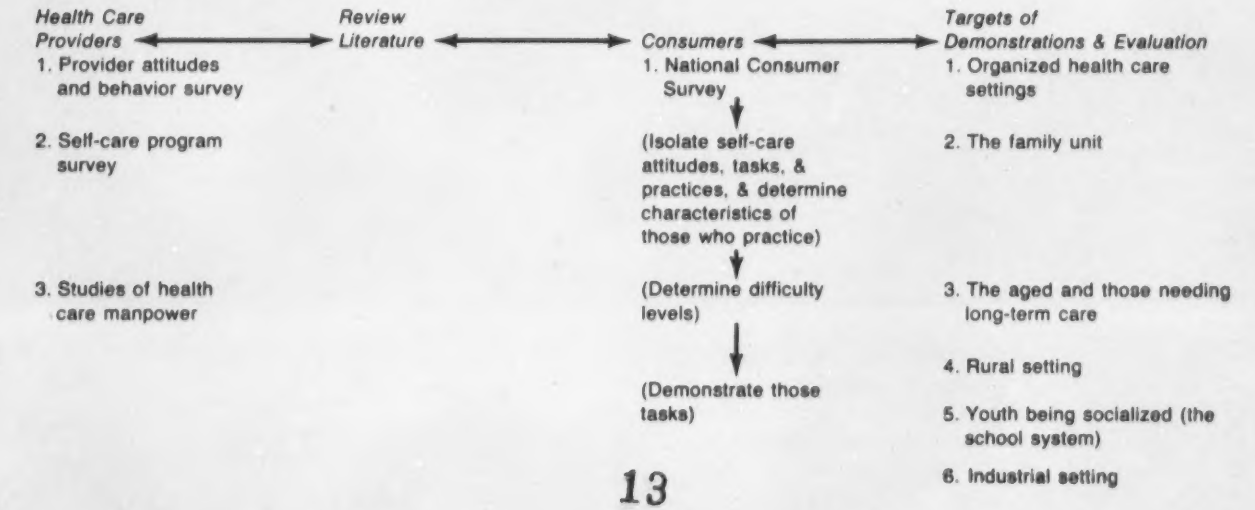
2. Consumer-oriented research

(a) A national survey of consumers is recommended. The survey is intended to reveal the current state of the population's health behavior and attitudes, and to aid in drawing inferences about the types of self-care tasks to be undertaken in demonstrations. The survey should, at the least, collect data on (1) population characteristics, (2) the population's incidence of health problems and responses to those problems, and (3) the population's attitudes, perceived needs, and general acceptability regarding self-care activities.

(b) To supplement the national survey, a review of literature on consumer health behavior is recommended. Special emphasis should be

Parameters of research

1. Comprehensive educational content
2. Self-care which substitutes for primary care
3. Dependent variables addressing, for example, attitudes, confidence, consumer skills, costs, efficiency of services, utilization patterns, mortality, hospitalization rates, and morbidity


Health Care Providers
Review Literature
Consumers
Targets of Demonstrations & Evaluation
1. Provider attitudes and behavior survey
2. Self-care program survey
3. Studies of health care manpower
1. National Consumer Survey
(Isolate self-care attitudes, tasks, & practices, & determine characteristics of those who practice)
(Determine difficulty levels)
(Demonstrate those tasks)
1. Organized health care settings
2. The family unit
3. The aged and those needing long-term care
4. Rural setting
5. Youth being socialized (the school system)
6. Industrial setting

given to findings on consumer "coping," by the National Institute of Mental Health, and research on consumer behavior, from the National Institutes of Health categorical disease programs.

3. Health care provider research

(a) Baseline information should be collected from existing programs of self-care. Also, provider attitudes toward self-care education and consumer initiative should be surveyed, as well as the current state of provider behavior in encouraging and fostering consumer initiative and self-care.

(b) Based upon survey findings, literature review, and demonstration experience, research on new health care manpower related to self-care programs will probably be indicated, such as manpower needs assessments, training, and field demonstration.

(c) There needs to be experimentation with new curricula for undergraduate students in the health professions. The curricula should address consumer/provider interaction.

4. Demonstrations

(a) Settings for demonstrating self-care practice or theory should include health maintenance organizations and other prepaid group practices, family practices, multiple specialty clinics, emergency medical services settings (in limited cases), public schools, chronic care and long-term care settings, youth service organizations, and industry.

(b) Populations for research and demonstration should include youth, especially in the school setting, and the elderly. Outcome variables for the latter should emphasize immediate improvement in the quality of life.

(c) The rural setting should be addressed through demonstration, but not as a solution to the scarcity of health care manpower and services. The implementation of experimental self-care projects should in no way diminish current efforts to reduce the scarcity of traditional health care services.

Appendices

Appendix A

"The 'Care' in Self-Care"
by George A. Silver, M.D.[1]

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Abstract[2]: This paper presents the view that in spite of all the discussion and debate surrounding the self-care issue, emphasis must still be placed on the "care" in self-care. There is a responsibility to care, no matter what the difficulties.

A startling comparison can be drawn between the pampered position of the clergy in medieval times and the position of the medical profession in recent times. Both were considered to be the elite, both the self-appointed hierarchies of their time. However, with the advancement of printing and the abandonment of Latin came those who challenged the privileges of the clergy. Similarly today, public education and the media have served to bring medical knowledge to vast numbers, and now there have arisen those who challenge all or part of the existing medical order. They view medicine as a self-perpetuating bureaucracy, once concerned with alleviating suffering, now a dehumanized mechanism.

Thus, the self-care movement is now seen as the solution to the problems of the current medical order. It is thought to be an economic remedy, a political remedy, and even a social remedy. Perhaps it should not be viewed as a cure-all, but rather as a social measure to increase current medical services. There is, therefore, a need for all the dimensions of self-care to be fully investigated in order for self-care to be a realizable goal. It needs to be completely researched, and its territory minutely mapped.

In a brilliant essay on the role of medicine as an integral factor in the helping professions, Francis Peabody made the point that the "secret of the care of the patient was caring for the patient."

We are living through very exciting, disturbing, unnerving times in every aspect of our lives: social, political, psychological, and personal. The pressures and demands are such that the best-intentioned and most thoughtful of us tend to be caught up in the wave of competing dogmas and equate belief with effect. In the intensity of that belief, we may lose sight of our responsibility to care. I would like this meeting to hold to a standard of subjective as well as objective concern: attention to the "care" as well as to the "self." It will be difficult.

The subject we have come together to discuss, ponder, and dissect is very much in the center of popular agitation today. For some it is the key to cost control, for others the key to equitable distribution or resources, and for some a crusade. Self-care cuts across conflicting medical opinions and lay interest trends.

Note the contrapuntal use of "medical" and "lay" in the last sentence. This generation may be the last one in which the terms "professional" and "lay" may be opposed. The historic nature of this development should not be overlooked, because in some ways it epitomizes the reasons for calling this conference.

It is interesting to note the parallels with the last years of medieval scholarship, when clerical and lay were the opposing terms. The clergy had the education, sophistication, knowledge, prestige, and power. The clergy was the elite, second only to the nobility and royalty; and in some places, second to none. The clergy was the beneficiary of extravagant largesse from the nobility and royalty. It was equally the beneficiary of the pittances scraped together by an impoverished and oppressed underclass, ignorant and unlettered, who made up the mass of mankind. A situation, one might add, not too different from that of many of the millions making up the mass of the third and fourth worlds today.

We can recall how powerfully privileged that upper class was in the persistence of the term, "benefit of clergy." If you could read and write, you needn't be tried in ordinary civil courts for certain crimes, but could lay claim to trial in ecclesiastical courts. In the civil courts, punishments meted out included a hand chopped off, ears cropped, an eye put out, branding, or most condign, to be hanged, drawn and quartered.

[1] Professor of Public Health, Yale University School of Medicine.
[2] Summarized by Jeanne A. Gillis, National Center for Health Services Research.

Ecclesiastical courts dealt more benignly with offenders. You were educated, a cleric, and would be dealt with in accord with your dignity and status, hardly ever corporal punishment; perhaps a few extra prayers or self-flagellation.

Why am I elaborating on this theme? Because medicine, as a profession; medical practice as an occupation; medical care as a specialty service—have come to be seen as the heirs of the medieval clergy; and the lay heirs in an increasingly populist, consumerist society, are in revolt. The privileges and perquisites of the elite are in danger, true; but in addition, very much as in the results of the protestant rebellion, the Reformation, all the attributes of the clerical elite will be eliminated along with the clergy.

In those times, it was printing that helped spread the message, that and the growth of preaching in the popular tongues. Dropping Latin gave everyone a claim to knowledge which was particularly important because the protestants had dispensed with the priest as a special intermediary with God. Everyone his own priest! The clergy was an unnecessary self-appointed hierarchy.

The parallel is uncanny. Public education, TV and radio, the media generally have brought medical knowledge to people. Increasingly, too, information has been circulated on the failures of the medical priesthood: mistakes, sure, but also their remedies and positive statements don't hold from one year to the next. And some of their remedies do more harm than good! Their gross humanity has been revealed. They aren't really a holy, self-sacrificing, patient-minded order. They're just like the rest of us: some greedy, some lazy, some stupid, some incompetent, some evil—and some all of these. By Apollo! They're not messengers of the gods, just fellow human beings!

So the new brotherhood of zealous medical reformers is at work, carrying on as a new generation of Luthers, Calvins, Zwinglis, and Huses. But on a medical substrate. It is clear that doctors, the medical profession, have deliberately mystified people, hiding the simple knowledge of diagnosis and therapy behind screens of arcane language and sophisticated flummery. It's time to return to plain talk. Not only that, it's time to get rid of the professional cheats altogether and take over responsibilities ourselves. The most oppressed—slaves and serfs in the medieval times; blacks and women today—lead in the destruction of the old order, challenging the medical professional dominance. This ministry doesn't require 12 years of intense application to only marginally relevant topics—a few weeks or months will do, immersion in a mystique is self-defeating, take care of matters yourself.

Some of the clergy join in the unmasking, long uncomfortable with the elaborate rituals of concealment and separation from their patients. They want to bring things together. Needless to say, they aren't always welcomed in the ranks of the heretics. In a revolutionary situation, all the old order must go! As in the French Revolution, when Lavoisier was executed because as a wealthy landowner he was a sinner against the people, this revolution also has no need of scientists. So that's one scenario for development of a self-care program.

Medicine is nine-tenths a professionally perpetuated mystery, self-aggrandizement of a sect, a bureaucracy like most bureaucracies interested primarily in its own survival, not the welfare of its clientele. Its original goal may have been to help suffering humanity; today its goal is self-preservation and that at an increasingly luxurious level. In the logical conclusion to this analogy, I would have to see not only the death of the clergy but atheism and the death of God. In our times, that would mean that sickness and suffering would cease to have any social ministration. People would fend for themselves. We won't go that far.

The self-care thesis at its most extravagantly militant preaches total divorce from professional considerations, disestablishment of the medical church, and elimination of any traditional medical participation in patient care. No matter how small a constituency this extreme position may have, it is important to keep it in mind, for a number of reasons.

In the first place, while it is true that the overwhelming majority of the "self-care" enthusiasts are moderates, like all of us here, with an appropriate perspective, who see this as a necessary and logical step to the improvement of medical care overall, not everyone is interested in that end. Some see it as an economic remedy—cost sparing; others as a political remedy—a substitute for an expensive national health service; and still others as a social remedy—status levelling through manpower redistribution. These are unstable alliances, since the confederates hope to attain mutually exclusive goals. With the extreme anti-professionals as a leadership cadre, the health of the people must suffer.

That was my chief reason for initiating this discussion from an historical perspective. I see the need for self-care as a social measure to augment effective medical services. After all, I am a physician with experience in medical practice and in medical care organization. I see a need for more and better knowledge of the workings of the human body to be more widely disseminated; of the need for the nature of disease, its manifestations, and its prevention, for health promotion activities and simple treatment to be more widely known. This knowledge is necessary for everyone, not just to save money by avoiding too many expensive contacts with costly professionals, overusing machinery and equipment. Not just to avoid producing added professionals to serve in underserved isolated and unpleasant places; or to take

care of people with whom the professionals are culturally incompatible. Nor is it that if people get to know these things you won't need a medical establishment at all. That knowledge is necessary so that people can make intelligent choices, because knowledge is the key to freedom of action. What democracy is in the political arena, that's what informed consent is in the medical arena.

In essence, we are here because the NCHSR wants to know what the interfaces are between self-care and medicine: what needs to be studied and investigated in the professional field that will make self-care a realizable goal. We're looking for researchable questions, not polemical ones. We need to establish the boundaries, map the terrain, determine the relations between social knowledge and medical knowledge; the channels from professional to lay understanding; the congruence of biomedical and biosocial research; the methodology of learning and the methodology of teaching these things.

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There is much to learn about the dimensions of self-care. True, there are already pioneers who have written dramatically of the possibilities. The pioneers have made their reconnaissance; where shall the next reconnoitering take place? Is there a time now, and a place for pilot programs? Future planning?

My own motto in life has been drawn from Leonhard Euler, the German mathematician who said, "Invert and proceed." Or you may prefer David Riesman's formulation, "Look at all the statements which seem true and question them." Either will serve for our deliberations.

Appendix B

"Self-Care: An International Perspective"
by Lowell S. Levin [1]

Abstract [2]: Two international meetings held in 1975 have focused attention on the self-care movement and concept. The first was held in Switzerland in March, and featured some of the theories of Ivan Illich, including his thesis on medicine as an institution of social control. Discussion also centered on the limits of medicine, and a reexamination of the role of medicine within the framework of the total social resource in health was encouraged. This was accomplished by focusing on the concept of limitation with the professional health resource.

The second, held in Copenhagen five months later, was the first international symposium on the role of the individual in primary health care. The goals of this meeting were to explore the lay resource in primary care, to clarify assumptions of role and function, to draw attention to relevant issues surrounding the self-care movement, and to identify areas where research is needed.

The discussions that evolved as a result of this second meeting were divided into three main categories. In the first, "Self-care: What is all the shouting about?" the question was reviewed of why self-care had emerged both as a concept and as a movement. Many contributing factors were discussed, but no satisfactory explanation found. Also, much variety in the level and expression of the self-care movement was reflected in the countries represented at this meeting. In the second, "Issues Relating to Self-care: its present and potential," the various issues and questions that have arisen with the emergence of the self-care movement were discussed. These issues covered seven different areas: philosophical-political, professional-lay relationships, economic-organizational-adminsitrative, ethical, legal, quality assurance and cost-effectiveness, and policy and procedural issues. In the third and final category, "Research Needs in Self-care," data available on self-care were shown to be lacking. This led to the suggestion that research be concentrated and conducted in the following areas: historical-social studies, clinical implications of self-care, economic-administrative, and educational research.[3]

Two international meetings relevant to self-care were held in Europe in 1975. The first, entitled "The Limits of Medicine" took place in Switzerland in March, 1975, and featured the conceptual shock waves of Ivan Illich whose thesis concerning medicine as an institution of social control needs no restatement for this group. Illich's reductionist views led one participant to ask the obvious question: "If the profession of medicine is to be abandoned or radically reduced, who or what shall take its place?" "Self-care," Illich responded. People can learn to take care of themselves and their families. Some left Davos feeling traumatized, titalated, or "took". Others sensed that the real significance of the Illich prescription and the debate it promulgated was its lack of a substantial rebuttal based on (1) data documenting the contribution of medical care to the health of society; and on (2) data denying the potential of self-care as a purpose-built alternative to professional medical care. In other words, participants who felt they were witness to a crime against logic were unable to muster much more than personal disbelief and discomfort to back their claim of absurdity. On the other hand, proponents of the reductionist theory could refer to McKeown's analysis of British data which show very late and rather modest contributions of medical intervention in the control of many of the infectious diseases of the last several centuries. Further, they could produce some startling data which, in fact, demonstrate an already impressive contribution of self-care and at the same time some of the hazards of professional medical care in terms of clinical as well as social iatrogenisis.

The contribution of the Swiss conference on the limits of medicine, it seems to me, was that it focused sharply on the concept of limitation in the effectiveness and appropriateness of the professional health resource. In effect, the result was to

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[1] Yale University School of Medicine, Department of Epidemiology and Public Health.

[2] Summarized by Jeanne A. Gillis, National Center for Health Services Research.

[3] *Social Policy* 7, No. 2 (1976).

encourage a perspective on the role of medicine in the context of the total social resource in health, forcing a fresh examination of assumptions upon which the social charter of medicine rests.

Five months after the conference, the Joint Center for Studies of Health Programs (UCLA-University of Copenhagen) convened the first international symposium on the role of the individual in primary health care. Twenty-nine scholars from four European countries, Israel, and the United States, met in Copenhagen for a week to explore the lay resource in primary care, clarify assumptions of role and function, draw attention to relevant technical, logistical, economic and social issues, and identify priority research needs.

Participants included administrators, health practitioners, and behavioral scientists. The meeting was prepared for and organized in such a way as to reduce conceptual and semantic confusion as much as possible and to facilitate interdisciplinary communication. But there was no doubt that the issue of lay initiatives in primary care drew out strong personal and professional values which did not always make consensus possible. Nevertheless, the issues were sharply etched as were requirements for research on self-care. It is my intention now to give you some feeling for the substance of these discussions in highly summarized form.

Self-care: what is all the shouting about?

The question of why self-care has emerged as a subject of special interest at this time dominated a good portion of early discussions and, indeed, was never satisfactorily answered. There appeared to be for some the nagging concern that self-care was being promulgated by a relatively small but strident minority of groups and individuals who were seeking redress for grievances sustained at the hands of the professional care system; or were in some way denied access to adequate professional care; or were attempting a challenge to the social control of medicine as part of a more diffuse political strategy. Others believed that interest in self-care was a reflection of larger and more profound areas of social discontent with the quality of life generally, e.g., loss of personal control, reaction against authority, antitechnology sentiment, etc.

It was argued that perhaps all of the above in various combinations and to varying degrees were present in the apparent rise in popular interest in self-care. But certainly, it was noted, we must take into account the shift in patterns of disease toward chronic illness [4] which, on practical logistical grounds, demand increased patient participation in management and rehabilitation.

Inadequacies in the health care system, particularly the matters of increased costs and maldistribution of personal resources, may in fact be more immediate causes of an apparent surge of interest in self-care. Indeed, some of the solutions to inequities in professional services could be considered as contributing, unwittingly, to the demystification of the professional resource. Functional redistribution of the physician's responsibilities, for example, could have made more apparent the availability of medical technology through relatively modest educational investments. Professor Maurice Backett of the University of Nottingham stated his view that self-care was the logical extension of the medical auxiliary. And, of course, greater understanding on the role of life-style in disease prevention, with its concomitant emphasis on individual decision-making and intervention, are keystone concepts in the construct of holistic and prospective medicine.

It was clear that there is a wide variation in both the level and expression of the so-called self-care movement in the countries represented at the Copenhagen symposium. The United States, and to a considerably lesser extent, Britain, appeared at more or less one end of the continuum, with the Scandinavian countries at the opposite end. This fact led quite naturally to speculation that interest in self-care as an accelerated resource may be more linked to the nature of the available health care organization and medical economics than to attributes of disease patterns or demand for more personal control over technology or authority. The apparent level of self-care practice extant was viewed as comparable among the six countries. Indeed, a recent study reported by Pederson of Denmark found that nearly 90 percent of all cases reported to a general practitioner had been relevantly self-treated prior to the medical contact. Fry reported on the Elliott-Binns study (1973) as showing "that some attempts at self-care and advice from others had been carried out by more than 95 percent of patients coming to see him." And on the basis of other British surveys, Fry concludes that only 20 percent of all symptom experiences result in a medical contact.

But it was clear that the matter of self-care as a concept, as a discrete component in the health care delivery system, as a focal interest in society and in the professions, was, with the exception of Britain, at a relatively low order of perception. Indeed some of the European participants seemed somewhat indifferent (at least initially) to the Illich prescription and rather surprised at the very lively interest their American colleagues displayed in self-care. However, when self-care was defined in terms of its functional potential as supplementary, substitutionary, and additive to professional services, the European participants were certainly heard from! On the whole, they appeared to be less interested in the emotive issues surrounding self-care, e.g., self-care as part of a consumer movement and as a factor of deprofessionalization, demystification, and dependency control, and

[4] From 50 to 80 percent in 40 years.

more interested in the efficacy of self-care in more classical terms of health outcomes.

From the standpoint of a European perspective on self-care, I think the Copenhagen symposium offers a useful reference point for establishing a broad agenda of issues and research challenges less parochially geared to the U.S. experience. There is, however, good reason to believe that the U.S. and Britain will very likely be the source of immediate international research initiatives in self-care, given their present levels of popular and professional interest, theoretical formulations, fragmentary but suggestive research, and already on-the-ground demonstrations of purposeful self-care education. There was clearly an interest on the part of our European colleagues to cooperate in international research on self-care and a plea that immediate and top priority be given to establishing an international scheme for the distribution of self-care materials, conceptual, research, and demonstration. The Joint Center for Studies of Health Programs (Copenhagen) has agreed to undertake this responsibility. John Williamson at Guy's Hospital School of Medicine (London) has since suggested a taxonomy and classification format for use by the Joint Center to ensure improved communication across cultures. A draft of the classification system apparently is now being circulated for review and comment.

I do not want to leave this discussion of Europe's interest in self-care without emphasizing that there are at least three academic centers of health care research which have expressed strong interest in self-care: The University of Copenhagen Institute of Social Medicine (Joint Center); The University of Nottingham, Department of Community Medicine); and Guy's Hospital Medical School, Department of General Practice. In addition, there is at least one informed group of scholars and medical practitioners in Britain that has looked thoughtfully at self-care practice and potential (chaired by Dr. John Fry, a general practitioner and member of the British Medical Council). And more recently, I understand that Professor Margaret Stacey's group at Essex also is undertaking work on self-care. The point is that there are established anchor points in Europe for cooperative international research.

Issues relating to self-care: its present and potential

It is difficult to present the issues raised in anything more than a cursory manner. My hope is that I can transmit the range of these issues and the thrust of their underlying concerns. And although little concensus was achieved, and the influence of the American participants was significant, several issues received sustained and rather universal interest. They can be assembled in the following categories:

(1) Philosophical-political issues. Recognizing the popular base of self-care, is it possible that the integrity of its contribution may be compromised through a new erstwhile partnership with the professional sector? The threat of professional dominance is at issue here. Further, with increases in lay technical competence in primary medical care, can one predict the emergence of a skill hierarch which could convert the lay resource into a new professional category?

The acceleration of self-care competence among laypersons could result in fundamental challenges to the perceived efficacy of the professional health care system thereby causing a weakening of public support for expansion or improvement of the system. Are we prepared to accept this eventuality and acknowledge the potential social benefits?

Will increased self-care competence diminish or enhance public participation in concerted social action to achieve individual and community protection? Can the concept of self-care be cast in terms sufficiently broad to include the political skills of consumerism without politicizing self-care to the point of jeopardizing its universality?

(2) Professional-lay relationship issues. Self care is a concept with deep roots in the populist values of self-control and self-determinism. Its development surely will result in demystifying professional functions and may cause a "re-writing" of medicine's social charter. What are the implications of this with regard to currently assumed "essential" functions of medicine *vis a vis* legitimization of illness and the provision of patient support (dependency) through transfer of responsibility (faith in medicine's mystique)?

Given that self-care is a civil right of laypersons with relatively few *de jurie* constraints; and given that there is a continuation of lay interest in expanding self-care; what are the criteria which might define the effective limits of self-care and its corollary, the effective limits of professional medical care?

A self-care competent population by definition would influence more than the re-distribution of lay-professional technical functions. We can also anticipate lay impact on many previously unchallenged definitions of normal, tolerable, preventable, curable, and ethical. What are the possible implications for the medical education of the public and the public education of medicine?

(3) Economic, organizational, administrative issues. One could theorize that a self-care competent society would impact heavily on medical-economic monopolies. But it is also reasonable to raise the issue of how the economic benefits would be re-distributed or, indeed, contribute further economic benefits to certain components of the medical-industrial complex.

Self-care as it exists today is organized around traditional family and cultural-social values. It is indigenous and very likely more acquired than

cognative. This has been the source of its integrity and durability. At the same time, family structure and patterns of social organization are in rapid flux. What are the implications of these trends for self-care development?

A key administrative issue was raised with regard to incentives to "bribe" the health and educational systems toward postures and programs more responsive to self-care development. There may well have to be leverage available to encourage promotion of self-care practices—given the suspicion that proof of better outcomes may not be sufficient in and of itself.

(4) Ethical issues. Many of the ethical issues surrounding the concept of self-care are consequent to its primary effect: the sharing of power through the redistribution of technical skills and the strengthening of lay initiatives in decision-making. The issues were expressed as concerns: What about damage? The doctors get away with murder—but can the family? What are the risks of false positives and false negatives? What are the risks of potentiation of medicines and what are the risks of unnecessary misery? (One device not available in self-care is malpractice insurance!) How much avoidable damage is society prepared to trade off against the health, social, and economic benefits of self-care?

Then there was the concern for "imposing" self-care on society as a whole. Perhaps there are those who prefer to remain passive and dependent. Maybe self-care should be more specifically geared to high risk groups (including inappropriate over-users of professional services).

On the other side of the coin is the question of induced patient dependency and the ethics of denying patients the opportunity for achieving greater self-control. This includes the matter of the ethical obligation to inform patients of their diagnosis, treatment options, and prognosis and to share the medical record with the patient as a civil right as well as a sound medical practice. What, in effect, are the justifiable grounds for *not* maximizing patient self-control and how can society assure that their criteria of access to information are being applied? Is the level of patient self-care competence a factor in the control of clinical and social iatrogenisis?

(5) Legal issues. Self-care is by and large unacknowledged in the legal literature. Statutes cover the practice of medicine, surgery, nursing, dentistry, pharmacy, etc., from the standpoint of the performance of those acts for compensation, gain or reward, received or expected. This appeared to be the case for the countries represented at the Copenhagen symposium. But there are, of course, a good number of *de facto* prohibitions which, although they do not possess the force of law nevertheless may impact on the public's interest and willingness to undertake to learn and apply certain procedures. One can anticipate, however, the possibility of court test (as occurred in California recently *re* a woman charged with the medicinal application of Yogurt to another woman). Those who engage in self-care education must be made cognizant of this potential, however marginal it might be. The more immediate and substantial issue is the possibility of professionals assuming *de jurie* constraints causing them to limit their educational efforts with laypersons to health procedures which do not cross over into areas of traditional medical functions.

(6) Quality assurance and cost effectiveness. Self-care as it is now practiced is subject to empirical testing, albeit the criteria of effect may not always be in agreement with professional criteria. Views of the efficacy of self-care practices now run the gamut from charges of "rampant empiricism," dangerous and ineffectual, to the view that they are overwhelmingly harmless, usually appropriate and, indeed, are what makes it possible to save any health care system from being swamped. The research of Poul Pedersen of Denmark and Ann Cartwright and John Fry of Britain support the latter view. Most of the illness most commonly experienced is self-limiting and rarely life threatening.

However, purposeful self-care education is proposed that goes considerably beyond the folk system and, as a consequence, has an obligation to test the efficacy and safety of primary medical procedures to be self-administered, without professional supervision, and without an established organizational framework for peer review and continuing education. Like other aspects of public education, once the skills are introduced they become, by definition, the public domain. But health care skills, unlike reading skills, demand periodic review for validity, improvement through new technology, and for some procedures, frequent use to maintain the skill. Also, situations change, thereby limiting the use of protocols and algorithms to those not requiring sophisticated symptoms analysis beyond the capability of the self-care educated. A point also was emphasized by a British investigator that the evaluation of self-care must take into account psychological, social, and philosophical variables which are unique outcomes of self-care (in contrast to professional medical care outcomes).

The Copenhagen symposium did not go beyond raising the issue of quality control in self-care education. There were no solutions offered. On the other hand, several discussants took the view that we can at least make sure that the primary care techniques suggested for transfer to the lay domain meet, in themselves, a standard of efficacy. It was noted that many established primary care procedures used by professionals probably would fail the test of efficacy *regardless* of who applies them!

Finally, several symposium participants agreed with the view that the issue of quality control and

cost effectiveness in self-care should not be limited to clinical trials or outcomes studies, but should include large measures of effect in terms of social change, impact on the professional care system, and net economic effects.

(7) Policy and procedural issues. Scholarly and professional attention to the potential of self-care is at a very early stage. Our European colleagues agreed that the natural forces of social change and the requirements of chronic disease management will most likely continue to place self-care in a strategic position. Purposeful development of self-care as a recognized component in the care system will require policy makers, administrators, behavioral scientists, and medical practitioners to re-think some of the basic assumptions upon which our present approach to health development rests. Conferences and seminars on self-care are useful now to stimulate interest, but the crucial need in the immediate future is a data base, preferably on an international scale. Secondly, we must make some decisions with regard to research priorities, again with technologies amendable to international comparisons.

This will mean challenging national research policies in health care to shift a substantial proportion of their research and demonstration support away from the present nearly exclusive emphasis on manipulations of the professional sector, e.g., professional manpower incentives, organizational reform, professional education, practice modalities, etc., to the lay resource, e.g., determination of self-care competency levels, self-care needs assessments, development strategies, etc. No one should underestimate the difficulties of such a policy shift, given the awesome professional constituancies supporting the present arrangement. Consumer groups interested in self-care are alone no match for the professional lobby.

Research needs in self-care

A. Preface.

From the outset of the Copenhagen discussions, it was clear that there were relatively little data on self-care practice, the needs it addresses or problems it may cause, or the nature of its interaction with social, political, technical, and organizational factors. All that could be established was that self-care was ubiguitous among cultures; that its specific effects were unclear; and that efforts to strengthen primary health care require that we account for all components in the delivery system, including the contribution of the individual and family. It was agreed that studies of the lay resource in primary care was an almost totally neglected area of research and rarely considered in health planning.

A commitment to self-care research should ensure that it is free of prejudgment. This caution reflected the Copenhagen participants' awareness that self-care research and demonstration must address such sensitive issues as efficacy of existing primary care technology, substitutionary potentials of self-care, lay skills in controlling the health transaction, and self-care implications for reducing iatrogenic effects.

A major block to self-care research—or a factor which may effect its ultimate usefulness in planning—could be the lack of a theoretical framework. One approach to this may be to examine self-care within the classical categories of health maintenance behavior, illness behavior, sick role behavior (prior to contact with professional health care), sick role behavior (post medical care contact), rehabilitation behavior, and chronic care behavior. This could at least provide a descriptive display in which we could identify gaps and incongruities in theory and research relevant to self-care. Further, and perhaps most important, such an analysis may reveal assumptive biases which result in failures to test the full implications of behaviors in terms of positive benefits (examples: delay and compliance).

Before proceeding to specific research recommendations, one other issue raised in Copenhagen must be mentioned. It was believed by several at the symposium that self-care research should be approached on a broad front. What is needed is a research strategy which recognizes that the nature of self-care behavior demands observations at several levels involving case analyses, critical incidents, and self-observation as well as survey research and large population studies.

Lay involvement in self-care research was given special attention. Self-care, by definition, lies beyond the purview of the professional component of the health care system. As such, self-care behaviors have not been defined, codified, or criteria of efficacy determined. Self-care practices exist for reasons and purposes assumed but not tested; the demand for modifications or additions to self-care are not necessarily predictable on the basis of professional judgment of needs or appropriateness. Criteria of use, effectiveness, and demand may not, in effect, conform to usual professional calibrations—in all or even most respects. It is necessary, therefore, to pursue a research strategy involving lay contributions to self-care theory building (including rationale and benefits), identification of variables affecting self-care practices, framing of hypotheses, and setting of outcome criteria.

B. Specific research recommendations

1. Historical-social studies

Description and specification of the present varieties of self-care in their historical development, as well as in their specific current manifestations, is required as the first phase in descriptive research. This would include the impact of culture,

political and religious ideologies, popular beliefs and attitudes on health in general and self-care in health in particular. Historical and social perspectives are likewise essential to an informed view of current manifestations of self-care.

A related question of historical and social importance is the role of the interest groups. Who is promoting self-care and why? Is it a "social movement"? This would call for a broad cross-national study of social forces supporting and opposing the present thrusts toward self-care, a specification of their intensity and significance in political-social terms, their probable impacts upon health systems and professionals, points of conflict, etc. Such a study also must seek to evaluate the contributions of political and economic factors, morbidity patterns, and attitudinal factors (anti-authority sentiments, etc.) to self-care.

2. Clinical implications of self-care

These studies would have to do with the issues of the efficacy and appropriateness of self-care practices. We know something about the intensity of self-care, little about its quality. Further, the introduction of new self-care techniques can and should be subject to clinical trial as in the case of other health practice innovations, recognizing the special problems noted earlier. This still leaves open the issue of selecting new self-care options, i.e., the issue of appropriateness, what criteria would pertain and how are they to be arrived at. (Hopefully our discussions here will focus on this matter.)

3. Economic, administrative studies

Some specific recommendations emerged:

- What are the present costs of self-care; which population groups bear them and which ones benefit from them? (input-output model)
- Which areas and processes of self-care can be distinguished on the basis of outcomes in terms of health impacts, net costs and democratic values? (outcome accounting matrices)
- What incentive devices can be designed to support efforts to increase self-care activities judged effective and prudent? (policy exploration research)
- Is there a relationship between the characteristics of the primary health care delivery system and the level of involvement of the individual in self-care? (in terms of payment system, multiple versus single source system, fee-or-free basis, solo or team primary care, level of work load of practitioner, extent of professional autonomy, integration of social service into primary health care services. (These would be studies of behavior—not outcomes)

4. Educational research

Self-care education research and development was viewed by the symposium participants as having two distinct thrusts. The first was work on testing techniques of disease- or situation-specific self-care interventions. These would include various devices to improve lay capability in preventive procedures (monitoring), minor therapeutic interventions (what to do until the doctor comes), and routine maintenance skills (insulin taking). Here the design and testing of protocols, algorithms, and patient instruction materials would be undertaken. A second thrust was that of designing, implementing, and evaluating long range self-care education programs where objectives could include skills in diagnosis and decision-making and a variety of medical care interventions, including those that are frankly substitutionary of professional functions. This could take the form of a sequential educational program for school children over a 10 to 12 year period with outcomes observed over an additional 10 to 15 years. A longitudinal design would allow testing a range of outcomes of special relevance to the concept of self-care, e.g., self-care skill maintenance levels, personal and social health decision-making behavior, use of professional services, control of clinical and social iatrogenesis, and medication behavior, as examples.

Finally, there is the important matter of professional education with regard to self-care. Unfortunately there was not sufficient opportunity for the symposium participants to do much more than express their concern that education of health professionals must be undertaken (at an early stage) to let them understand their advisory role in self-care. It might be interesting to experiment with educational modalities which give the health professional student an opportunity to learn from laypersons regarding self-care practices and their utility—establishing the ethic that professional care in health is truly supplementary to self-care which accounts for the overwhelming proportion of continuous health care provided on a day to day basis.

In closing: Fry offers an important caveat regarding self-care research:

> Self-care cannot be studied in isolation. The whole process of primary care, that involves self-care and first contact medical care, . . . must be studied in order that the roles of the public and the medical, nursing and social work professions can be best defined and applied.[6]

[6] John Fry, "Self-care: It's Place in the Total Health Care System," report by an independent working party (September, 1975).

Appendix C

"Health Beliefs of the U.S. Population: Implications of Self-care" [1]

by Gretchen V. Fleming
and Ronald Andersen, Ph.D.[2]

Summary [3]: Fleming and Andersen address the potential for the self-care movement's growth in the United States by examining the available literature and determining whether it supports assumptions which are made by the movement. Such assumptions are: that medical care should not be given preeminence in our society, that people are not getting what they want from the existing medical care system, that consumer independence is a growing value, and that some primary care tasks can and should be undertaken by consumers.

The authors review existing research to determine the extent to which the assumptions of the movement might be supported by beliefs and attitudes of the population. The cited survey findings address, e.g., the value of health to Americans; satisfaction with medical services; the value of individual independence on health matters, and its complement, consumer dependence upon the medical model; and the level of health knowledge of the U.S. population.

In general, the authors conclude that the potential for successful growth of the movement has shown some improvement in recent years. The trends, they say, hint that people value medicine and are not particularly disappointed by their own doctors, but there is some growth in consumer self-confidence regarding health matters, and a growing criticism of professional motivation and the quality of health care. Further, the movement stresses reform instead of revolution, so it could be considered a candidate for success. But, unfortunately, those who would benefit most could be the least-likely followers of the movement, as preliminary studies indicate those who would be interested are young, white, suburban, educated, and financially secure.

The authors proscribe needed additional research, and offer caveats regarding the findings they cite. For example, an assumption of the authors is that expressed dissatisfaction with medical services indicates the motivation to seek alternative forms of care. Also, it is possible that expressed scepticism toward medical services may just indicate a "fatalism" toward health.

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[1] *Perspectives* Series, Center for Health Administration Studies, University of Chicago (64 pp.).

[2] Center for Health Administration Studies, University of Chicago.

[3] Summarized by John D. Gallicchio, National Center for Health Services Research.

(NOTE: This paper was published by the Center for Health Administration Studies, University of Chicago, *Perspectives Series*, No. A-11. Because of its current availability, it is omitted here.)

Appendix D

Research and Demonstration Issues in Self-Care: Measuring the Decline of Medicocentrism

by Lawrence W. Green, Dr.P.H.,**
Stanley H. Werlin, M.B.A.,***
Helen H. Schauffler, B.A.***
and Charles H. Avery, M.D.***

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Summary: The origins of the current emergence of consumer health education in self-care is a reflection of two converging trends: the increased popularity of patient education programs, and the growing awareness on the part of consumers that they are indeed capable of rational, sophisticated self-help. Such factors as the movement toward consumer participation in government programs and community development, the self-directed behavior and behavior modification movement, the evolution of nursing theory and practice from "helping the helpless" toward facilitating self-care, and the evolution of group dynamics and self-help groups have all contributed to this trend. The medical self-care programs inspired by these social currents include such diverse subject matter as self-throat culture, arthritis, gynecological prevention, hypertension, and other condition-specific topics, as well as more comprehensive self-care programs covering a wide span of activities. Most of these projects have not existed for sufficient time to have conducted and reported an evaluation of their impact on participants' behavior and health status. Such evaluations are clearly needed before medical self-care programs are encouraged to proliferate as many other "unproven" social programs have. Where possible, such evaluations should be designed on a prospective basis and built into the educational program, rather than imposed retrospectively. This can avoid difficulties with inadequate or unavailable baseline data, inability to identify control and experimental groups, and non-comparable or non-uniform data across study groups.

The relatively unevaluated field of medical self-care programs suggests a number of important research and demonstration issues. These include measurements of attitudinal change, behavioral outcome, manpower implications, cost-benefit trade-offs, the technical limits of self-care, the applicability of self-care education to various population groups, and the utility of consumer algorithms. A major need in the field is the development of standardized measures of program input and output to facilitate comparison of results across studies. A federal program of replicative studies on these research and demonstration issues would offer the possibility of providing both substantive knowledge gains in the self-care field and results potentially generalizable to the larger field of health education program evaluation.

Introduction

Medicocentricity, like ethno and egocentricity, takes many forms. The allied health manpower movement has succeeded in eroding one form, the virtual monopoly of diagnostic functions and the concentration of therapeutic functions in the hands of the physician. Once some of these functions had been wrested from the medical profession, the veil lifted from a variety of medical procedures. It was found that these could be spelled out in fail-safe protocols for the training of physicians' assistants, nurse practitioners and even ambulance drivers. The next logical step in the decline of medicocentrism proceeded rapidly thereafter: it soon became much easier to transfer more of these functions to the consumer or patient himself. This has led to a sudden expansion in recent years of a class of health education activities now called self-care programs. The conceptual basis of these consumer self-care programs did not in fact originate in the medical care system itself. Rather, as this analysis will show, self-care concepts and related forms of consumer participation in assessing and solving problems has long been an integral part of the research and practice in many of the other helping professions.

Purpose and scope

This paper will examine some of the problems and prospects for demonstration and evaluation of

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** Assistant Dean for Continuing Education, and Head, Division of Health Education; Associate Professor in Departments of Public Health Administration, Population Dynamics, and Behavioral Sciences, School of Hygiene and Public Health, Johns Hopkins University, Baltimore, Maryland.

*** Health Care Group, Arthur D. Little, Inc., Cambridge, Massachusetts.

self-care in medicine and health. For the purposes of this paper, self-care will be defined as consumer performance of activities traditionally performed by providers. Recognizing the relative paucity of experience with patient activation * in medicine, many of the propositions developed here will draw upon more extensive but parallel experience with activated consumers or clients in education, behavioral and clinical psychology, public health, marketing, social work, community development and similar fields.

This paper is also based on data collected either by site visit or through documents and telephone interviews with fifteen self-care programs in which self-care was defined as the performance by consumers of actions traditionally carried out by health care providers. The self-care programs surveyed included programs in which consumers were performing on their own behalf what professionals had previously done for them. A sixteenth program will be described in more detail as a case study. The range of activities found in the sixteen programs studied is described below.

Six of the sixteen programs can be described as *comprehensive* self-care programs: the Reston-Georgetown (Virginia) program; the Regional Self-help program sponsored by Intermountain Regional Medical Program (Salt Lake City), the North Carolina Memorial Hospital Program (Chapel Hill), the Peter Bent Brigham Hospital Program (Boston), the University of Arizona Self-provider Project, and the Georgetown Activated Patient program. Seven programs addressed *chronic diseases:* The Diabetes Education Center (Minnesota), Central New York RMP (Diabetes program and Home Dialysis program), Group Health Cooperative of Puget Sound (two programs—diabetes and hypertension), the Intermountain RMPs arthritis program, and the Johns Hopkins asthma project. One program, the Freestanding Women's Health Center in Boston, addressed preventive care in gynecology.

Finally, two other programs are described: the Home Throat Culture program of the Columbia Medical Plan in Maryland and the Monroe County (New York) gonorrhea self-screening program. Most programs rely on small group or one-to-one educational contact; the North Carolina Memorial Hospital relies primarily on programmed instruction.

Conceptual origins of self-care

With the emerging array of current activity in medical self-care, much of it without precedent in the medical literature per se, it is imperative that the research experience with self-help programming in other spheres of human service be reviewed. Such a review should help to avoid the repetition of costly historical errors and to suggest hypotheses and methodologies to be used in evaluating self-care in the medical sphere.

The consumer participation movement: This section will not attempt to review the history of the voluntary health and welfare movement, or the community development movement. Both of these are pertinent to the self-care movement but both have been extensively reviewed in the past and summarized in recent reviews of community participation in health services.[1-15] The two aspects of these movements that are most germane to the emerging self-care movement and in need of closer inspection here are: (1) the attempts to measure citizen participation and its effects on health care, and (2) the effects of legislating requirements for citizen participation.

Silver has already noted the need for "evidence of the value—or lack of it—in consumer participation and control."[14] A few methodological advances and empirical studies were developing at the time of his review and are now available for adaptation to self-care evaluation.[16-21] The case study method was predominant, but recent developments combining content analysis of discussions at meetings of consumers and providers with formal interviews have offered ways of assessing consumer sophistication *vis-a-vis* the health care system.[18-21] This approach to measuring consumer autonomy might be extended to include affective, as well as cognitive dimensions. If the concept of the "activated patient," for example, includes the temerity of the patient in questioning his physician, then a measure of assertiveness[22] would be a legitimate criterion of success in self-care programs.

Silver also noted that the problem of evaluation in consumer participation would be as much a conceptual problem as a technical one.[14] Some assessments of consumer participation within the framework of health education have provided a degree of conceptual clarification pertinent to evaluation of self-care programs.[23-26] Wang *et al,* for example, have delineated program components, intermediate objectives and long-term objectives in a program designed to involve inner city youth more actively in the extended activities of the community pediatric center.[26] Galiher, *et al,* have attempted to define consumerism in relation to health and to delineate various levels at which consumers can participate in health decision making,[23] and Green has offered a variety of hypotheses on measurable benefits of "constructive consumerism" in health care systems.[24, 27]

The second aspect of the consumer participation movement which must concern those who would expect consumers to embrace the self-care movement is the legal aspect. The Community Action Programs (CAP) established under Title II of the Economic Opportunity Act of 1964 moved con-

* *Patient activation* has emerged in the terminology of the health education field in recent years to indicate enhancement of patient involvement in personal health care through teaching of self-care skills (physical) and principles of prevention.

sumer participation from a matter of voluntary action to a matter of public policy. Community action was suddenly defined in legal terms which carried both opportunities and new obligations for the poor.[28] "Maximum feasible participation" was further legislated in P.L. 89–749 in 1965 (authorizing the establishment of Regional Medical Programs) and in the Model Cities Demonstration Act of 1966.

For all of the good intentions behind the consumer participation movement, its legislated implementation was misunderstood or mistrusted by many professionals and consumers. The "Maximum Feasible Misunderstanding" created by the law is summarized by Moynihan:

> . . . in making its way through the maze of the Executive Office Building it had acquired a managerial gloss that—while never fully, or even partially, intended by its original sponsors—nonetheless proved decisive in its adoption by the mandarins of the Budget Bureau. Community action was originally seen as a means of shaping unorganized and even disorganized city dwellers into a coherent and self-conscious group, if necessary by techniques of protest and opposition to established authority. Somehow, however, the higher civil service came to see it as a means for coordinating at the community level the array of conflicting and overlapping departmental programs that proceeded from Washington . . . (p. 11)[31]

The co-optation of consumer participants in managerial functions undermined the intent of the legislation and left many volunteer participants feeling exploited and suspicious of governmental purposes. If the self-care movement becomes similarly enmeshed in governmental relations with health care providers and agencies, it is likely to take a different form, or at least a different flavor for the consumer, than it now takes in the programs under study today. This leads us to caution against extrapolating from evaluations of current self-care activities to results that could be expected generally under a universal program sponsored by the government. This caution is not merely a standard caveat on generalizability, but has special meaning in relation to activities in which voluntary participation of consumers becomes qualitatively a different variable when it is required by law.

The lesson from governmental implementation of "maximum feasible participation" laws is not necessarily that governmental support should not be offered to self-care programs, but it should be offered with carefully designed safeguards for the voluntary character of the programs.

Self-directed behavior and behavior modification: Whereas the citizen participation movement in health care is a pervasive but virtually unevaluated precedent for self-care, the behavior modification movement is a limited but rigorously evaluated precedent. The early applications of behavior modification techniques to health habits were tightly controlled experiments in which the subjects were voluntary participants but the rewards were designed and allotted by the experimenter. Increasingly, operant rewards have been designed for control by the subject (e.g., self-monitoring charts), to the point that the technology of behavior modification has been transferred to the lay public in the form of "self-control," "self-determination," and "biofeedback" manuals.[32-34]

The training of professionals to use behavior modification techniques increasingly emphasizes the application of reinforcers that patients, clients or subjects can use in their own home environment.[35] The early work of Kanfer and associates on the conditioning of self-reinforcing responses, based on an analogue to self-confidence training,[36,37] led to the clinical teaching of techniques for self-regulation (called "instigation therapy").[38,39] This and related techniques applying principles of operant conditioning were subsequently developed to enable individuals to employ them at home with a minimum of professional supervision. The most notable applications have been with eating behavior and obesity control[40-44] and smoking cessation.[45-47]

Nursing leadership in self-care: The discrepancies between patient and physician expectations under traditional systems of medical care suggest two other precedents for the self-care movement which deserves at least acknowledgement if not a thorough review. One is the long-term but recently formalized shift in *nursing* theory and practice away from the Nightingale model of helping the helpless to the current themes of self-care as formalized by the Nursing Development Conference Group.[48] The transition spans a century and is graphically illustrated by the series of charts reproduced below, contrasting the definitions and concepts of nursing from Nightingale[49] through Shaw,[50] Harmer,[51] Frederick and Northam,[52] Henderson,[53] and Orem.[54]

Another departure from the physician as the point of reference in self-care is the literature on self-help groups.

Group dynamics and self-help groups: Rather than relying on health professionals for support and guidance in matters of prevention, treatment and rehabilitation, many consumers and patients have found greater credibility or compatability with others who shared the problem or concern. The early precedents for this aspect of the self-care movement provide an instructive documentation of the efficacy of self-care.

Commonality of physical condition on health problems tends to give groups a cohesiveness if not an initial attractiveness.[55] Such grouping has been found effective in educational approaches to changing health behavior among alcoholics,[56]

obese patients,[57] neighbors meeting on accident prevention,[58] ambulatory hypertensive patients,[59] parents of children with rheumatic fever,[60] ulcer patients,[61] adult cardiacs,[62] parents in child health conferences,[63] and most frequently, diabetics.[64] The effectiveness of bringing together individuals who share common health problems appears to be based not only in the tendency to trust and conform to the judgment of others who have the same problem (which was experimentally demonstrated among orthopedically handicapped subjects),[65] but also in the quality of pertinent and understandable discussion and mutual reinforcement that occurs among participants in such groups. If such groups of patients can also be organized with some socioeconomic homogeneity, the discussion of solutions to common problems is also made more relevant, credible and applicable to the individuals participating.

The relative effectiveness of the group discussion-decision method over more didactic methods of education and behavioral influence has been well known to health educators since the early experiments of Kurt Lewin on changing food habits during the war years,[66] and the later, more extensive experiments of Betty Bond comparing group discussions with lectures to encourage breast examinations. Bond conducted 42 discussion meetings and 33 lectures with 933 women. Women exposed to the discussion-decision method subsequently had a higher rate of physician visits for breast examinations, a larger proportion established the habit of breast self-examination, and a greater percentage reported to a physician to demonstrate their technique of breast self-examination.[67]

Survey of current programs

Program descriptions: As noted on page one, 15 self-care projects were contacted and/or site visited as part of this research: six of them comprehensive in their orientation to health problems, seven focused on chronic diseases, and three on preventive or screening activities. In each site, consumers are taught to become providers of care for themselves.

The six "comprehensive" self-care programs differ somewhat in scope and approach, but all have in common self-care for a wide variety of problems or conditions, and all feature a combination of (1) presentation of information about prevention for a number of conditions, and (2) instruction to consumers in performing on their own behalf what health providers had traditionally performed. The most widely publicized of these programs is the Activated Patient Program of the Georgetown University Center for Continuing Health Education. The Georgetown program includes presentations in the following areas: prevention of arteriosclerosis, motor vehicle accident, cirrhosis, stroke, breast cancer, uterine cancer, and rheumatic heart disease; compliance with medical regimens; hypertension; nutrition; growth and development; common childhood illnesses; contraception, family planning, and venereal disease; medications; alcoholism; mental health and family relations; yoga; automation in health care; and innovation in health care. Many of the presentations are informational in nature, alerting consumers to causes, warning signs, and sensible personal health behavior. With respect to teaching patients to perform procedures on their own behalf the course teaches self-administered blood pressure, ear wax irrigation, hyposensitization shots, and emphasizes first aid (bites, artificial resuscitation, serious bleeding, heart attack, shock, sprains, brusies, etc.). The most interesting aspect of the course is its use of checklists for self-care of common childhood diseases. The checklists include sections on general information, important points to remember in treatment, and when to call a physician.

The Regional Self-Help Medical Care Training Project sponsored by the Intermountain Regional Medical Program was patterned after the Activated Patient project. This program uses much of the course content of the Activated Patient program with an emphasis on first aid and emergency aid. The course includes basic first aid and also incorporates cardiopulmonary resuscitation and emergency childbirth. The emphasis of the program on first aid and emergency care derives from the distances of the rural populations from medical facilities.

The Reston-Georgetown program uses a somewhat different format for its self-care education. This program relies heavily on the use of decision-making protocols or algorithms for 65 common complaints or problems in fourteen categories: emergencies; common injuries; poisons; upper respiratory problems; common skin disorders; childhood rashes with fever; arthritis; back pain and musculo-skeletal problems; nervousness and neurologic problems; chest pain and shortness of breath; eye problems; digestive tract; urinary tract; gynecological problems; and sexual problems. The algorithms are visual flowcharts designed to assist consumers in determining when it is appropriate to see a physician and when to apply a well-defined (in the protocol) home treatment. The algorithms have attempted to identify possible emergent conditions early and to concentrate on conditions affecting a majority of patients. After a brief introduction to each condition, each protocol defines appropriate home treatment, what to expect in a physician's office, and presents its visual flow chart. The Reston-Georgetown program also includes an educational component on how to use the health care system.

The North Carolina Memorial Hospital program is similar to the Reston-Georgetown program in

terms of its foci. The distinguishing feature of this program is its use of programmed instruction rather than patient algorithms.

Both the University of Arizona Self-Provider Project and the Peter Bent Brigham Hospital program are less comprehensive than the foregoing four programs, although they are still multiple focus programs. The Self-Provider Project is aimed primarily at identification of risk factors for certain diseases and their effect on health status. After an initial individual health hazard screening, the program concentrates on providing education on risk factors associated with, and control of: heart disease, hypertension, lung diseases, depression, and cancer of the breast, cervix, colon, and rectum. The Peter Bent Brigham program is similar to the other four programs in featuring education on bodily function; the prevention and treatment of common adult illnesses; prevention and treatment of common childhood diseases; adolescent problems; prescriptions, drugs, and over-the-counter medications; growth and development; and patient rights.

The remaining nine programs are all disease-specific programs relating to diabetes (3), hypertension (1), arthritis (1), kidney disease (1), gynecological prevention (1), self throat culture (1), and self screening for gonorrhea (1). Each of the fifteen projects is described in a recently completed report to the Office of the Assistant Secretary for Planning and Evaluation/Health, DHEW.*

The definition of self-care as "the performance for oneself of actions normally performed by health care providers" restricts the scope of self-care activities to physical activities, for the most part. Acquisition of knowledge about appropriate diet for diabetes, for example, is not within the realm of self-care according to this definition of the term. The performance of the process of diagnosing oneself when one formerly relied on a physician to do so is probably the only non-physical activity that qualifies under this definition of self-care. Listed below are the activities from the fifteen surveyed programs which we believe fall under the rubric of self-care defined as the assumption by consumers of traditional provider activities. In our opinion, this list is a reasonable definition of the state of the art of self-care according to this definition. It does not include basic prevention activities which consumers may and should take which providers have not themselves traditionally provided or controlled.

Self-care activities:

- Diagnosis of common symptoms or conditions which occur frequently but need not lead to a physician visit (included in most of the comprehensive self-care programs, notably in the patient algorithms used in the Reston-Georgetown program)
- Insulin injection (diabetes education programs)
- Urine testing (diabetes education programs, and the North Carolina Memorial Hosptial)
- Breast self-examination (Freestanding Women's Health Center and North Carolina Memorial Hospital)
- Cervical self-examination (Freestanding Women's Health Center)
- First aid for common injuries (comprehensive self-care programs)
- Emergency care
  - —cardiopulmonary resuscitation (Intermountain RMP Regional Self-Help Program)
  - —emergency childbirth (Intermountain RMP Regional Self-Help Program)
  - —other emergencies (comprehensive self-care programs)
- Taking blood pressure (North Carolina Memorial Hospital, Activated Patient, Group Health Cooperative, IRMP Self-Help Program)
- Throat culture (Columbia Medical Plan Program)
- Hyposensitization injections (Activated Patient)
- Ear Wax irrigation (Activated Patient)
- Kidney dialysis (Central New York RMP)
- Physical therapy for arthritis (IRMP Arthritis Project)
- Self-medication for asthmatics who had previously depended on an emergency room (John Hopkins).

Evaluation in projects surveyed: In the fifteen programs surveyed, relatively little impact evaluation has been conducted so far, although a few programs plan more rigorous evaluation. The evaluation of the asthma project will be described in the section of the report entitled "A Case Study." For many programs, conducting evaluation of the program's impact on patient health status would require additional funding or rebudgeting to an extent that would jeopardize the program itself. Others have not existed for a sufficient time to permit the formulation of an impact study. Most programs have either conducted short-term evaluations of program effectiveness which do not address the issue of long-term sustained impact, or process evaluations which have measured patient satisfaction with the educational program or patient perception of how to improve materials, lectures, etc. It would be particularly interesting to evaluate the results of comprehensive

* Arthur D. Little, Inc., *A Survey of Consumer Health Education Programs* (January 1976).

self-care programs with emphasis on utilization of health services before and after such educational interventions, since these programs address a wide range of self-care issues.

The state of evaluation in the self-care programs surveyed is described below:

- Both the Monroe County gonorrhea screening program and the Columbia Medical Plan Throat Culture program have carefully evaluated their results. Self-screening for gonorrhea has encountered some difficulties, while throat cultures have been shown reasonably reliable.
- The Group Health Cooperative of Puget Sound diabetes program hopes to implement a long-term experimental impact evaluation design to follow patients for up to one year after participation in the educational program. To date, the program has conducted measurement of knowledge and skills via pre-test and immediate post-test, together with subjective process evaluation by participants.
- The Group Health Cooperative of Puget Sound hypertension program conducts subjective process evaluation, and have proposed the use of a long-term experimental design using a pre-test and periodic post-tests to measure patient attitudes, knowledge and skill levels.
- The Georgetown Center for Continuing Education Activated Patient program for collected anecdotal evidence of program impact. More rigorous impact evaluation was being planned.
- The Intermountain RMP Regional Self-Help program had collected self-reported post-course data on patient behavior in the first year, but neither pre-test data nor control groups were available for comparison. Systematic evaluation was planned for the second year of the project.
- The North Carolina Memorial Hospital program measures post-course patient knowledge immediately with a questionnaire. Long-term impact evaluation had not been planned.
- The University of Arizona Self-Provider project was in the process of planning a formal evaluation of its efforts. The evaluation will include patient rescreening at stated intervals following educational intervention to measure changes in risks factors, and a pre-post questionnaire to measure changes in attitudes, knowledge, and behavior over an extended time period.
- The Diabetes Education Center measures, on a short-term basis, patient knowledge level and health status. The program also measures patient satisfaction with the educational process. No long-term evaluation is conducted.
- The Reston-Georgetown program is currently planning an impact evaluation design. The program is located within a health maintenance organization with a well-defined, essentially captive population, a highly desirable "laboratory" for impact evaluation studies.
- The Freestanding Women's Health Center measures patient satisfaction with the care and educational process.
- Peter Bent Brigham Hospital's program conducts a process evaluation aimed primarily at monitoring patient satisfaction.
- The Intermountain Arthritis Project has presumably conducted an evaluation, since it is required to do so by RMP. No data on their evaluation was available to ADL. Similar considerations apply to Central New York RMP programs.

Summary of major observations: From the survey of self-care programs we note the recent emergence of comprehensive (many topics, many educational sessions) self-care programs. Six of these programs were described in the accompanying text, and we are aware of three other RMP-based programs as well. The development of these programs, most of which are still in their infancy, signals a new trend in consumer health education programs toward multiple focus, self-diagnosis/self-help/self-care programming. We have noted even in the few programs we identified, the expansion and popularization of this type of program both in professional circles and in the health educational literature.

A second major finding is that consumers are being educated more than ever before to assume responsibility for tasks previously conducted by health providers. The activities we identified were listed in the text of this chapter previously, and encompass self-diagnosis, self-screening and self-treatment tasks.

Third, the emergence of the patient algorithm or checklist for medical decision-making, used in the Reston-Georgetown program and the Activated Patient program, is a new technology of potentially major significance. The application of a written, precisely defined protocol for diagnosing and treating minor complaints (and for knowing when they are more serious) is a method which, if proven effective, can be used in a wide-spread manner with important implications for reducing the pressure on the ambulatory care delivery system and its manpower.

Finally, we have found that evaluation efforts have been limited in this field primarily to measurement of patient knowledge, attitudes, skill and behavior over very short time periods, and to process evaluation of patient satisfaction with educational programs and/or patient perception of educational materials and methods to improve

them. Furthermore, this level of evaluation was not always reached in the comprehensive self-care programs. No long-term impact evaluations were identified in the programs we surveyed. On a more hopeful note, however, many of the programs described here were planning to design and implement long-term impact evaluations. Such evaluations are to be encouraged if we hope to ascertain the effectiveness of self-care programs.

Research and demonstration issues

Measuring attitudinal change: An area of extensive prior experience and research related to self-care is the psychological study of a personality or attitudinal construct called internal control of reinforcement, introduced by Rotter in 1954, now generally called locus of control. The prodigous flow of research on this subject now exceeds 1200 documents.[68] The bibliography of Throop and MacDonald[69] and the review by Joe[70] provide the most comprehensive outlines of the literature in this aspect of belief in one's ability to control external forces or be controlled by them.

The indications that locus of control can be shifted from external to internal on belief scales through "internality training" in areas such as rehabilitation[71-72] makes this variable most relevant to the potential evaluation of self-care programs.

Specific instruments to measure some aspect of internality or to place individuals on a scale of internal vs. external locus of control have been developed and widely standardized.[73-90] The I-E scale developed by Rotter[82] has been the most extensively employed of these measures with over eighty published applications of his original index.[90] The several variants for application with children,[73-81] youth,[87-88] and addicts[87] give greater sensitivity to the measurement of locus of control in these groups. A scale has been recently developed to measure locus of control specifically in relation to health.[91]

The utility of the Health Locus of Control Scale (HLC) in evaluating self-care programs is that it provides an intermediate measure of program outcome that is known to have predictive validity for health behavior.[91] It also has construct validity insofar as the purpose of self-care programs is to increase self-care behavior through a process of increasing the self-confidence of patients or consumers in controlling the forces that influence their own health.[92, 93]

Strickland noted eleven studies in which positive relationships were found between internal locus of control scores on the more general scale and health behavior.[94] Instances of negative findings,[95, 96] have been attributed to the use of the generalized I-E scale rather than the more specific HLC scale,[91] and the failure of investigators to treat the value placed on health as a separate variable.[97] When high valuation of health relative to other values[98] is taken into account, the prediction of health actions from internal locus of control is greatly increased.[91, 99, 100]

Thus, it will not be sufficient for self-care programs to increase internality of control in patients or consumers unless they already place a high value on the health goal or practice advocated. But if they value the health goal or practice, their internal control of reinforcement becomes crucial to their adoption of self-care practice. Measurement of these two predisposing variables (HLC and value placed on self-care) is therefore as important as measuring health knowledge.

Research and demonstration efforts in self-care should also include monitoring of the anticipated by-products of the decline of medicocentrism, namely the attitudes of patients and consumers toward providers and medical care services. At least five measures of patient attitudes toward doctors and medical care appear to have been published on the basis of standard methods of scale construction.[101] Zyzanski *et al,* have provided a Thurston scale of patient attitudes toward the competence and personal qualities of physicians.[102, 103] Franklin and McLemore also used Thurston methods to develop an index of attitudes toward student health services. Andersen[105] and Suchman[106] used Guttman scaling criteria to develop measures of attitudes toward health services and quality of care. Suchman focused on doubts of ethnic groups about the claims of professional medicine and desires to check on doctors and their behavior, but his findings were not replicated by Berkanovic and Reeder[107] or by Geertsen *et al,*[108] in populations with different self-care and popular medical orientations than Suchman's New York sample. Ware and Snyder have used factor analysis to identify more detailed dimensions underlying patient satisfaction with doctors and medical care.[109]

The reason for urging study of this variable in future evaluations of self-care programs is to provide for a response to the concerns of the medical community over disruption of doctor-patient relationships and eroding of patient confidence in medical treatment. The trend in self-care away from the traditional doctor-patient relationship is probably inescapable,[110] but whether this necessarily jeopardizes quality of care and compliance with prescribed regimens is a debatable question deserving of research as self-care programs progress.

It is an error for the medical community to assume that the "traditional" doctor-patient relationship was one of congruent expectations. Several investigations in the 1950s revealed major discrepancies between lay expectations and professionals' views of their role in health care.[111-113] Subsequent studies showed that even the patients

of higher socio-economic status, who tend to be more congruent with professionals in their expectations, do not have their expectations fulfilled by providers. [114-116] Furthermore, it is not necessarily the case that failure to meet patient expectations leads to non-compliance. [117] It is sometimes the case that patients have no firmly established expectations, especially with regard to specialized care, [118] which would be the rule rather than the exception in a system which encouraged self-care. Finally, the few precedents in which health plans encourage a degree of self-care and emphasize consumer education indicate that consumer behavior and expectations for utilization of health services become highly congruent with the expectations of providers. [119-124]

It is notable that these few precedents are of recent vintage. In a review of 450 articles describing pre-1970 patient education programs, the American Hospital Association found that "No program described endeavored to link educational services with illness recurrence or readmission problems." [126]

Measuring behavioral outcomes: Standardized measures of behavioral outcomes are better developed than measures of the antecedent and process variables discussed above, but agreement on methods and procedures for collecting, analyzing and interpreting behavioral methods is far from unanimous. The most extensive methodological work has been with indices of health service utilization. [127] Recent reviews of the literature, however, reveal wide discrepancies on criteria of "adequate" or "appropriate" utilization in terms of delay, [128-129] and the frequency or duration of return appointments. [130-136]

Larger discrepancies are found in the measurement of preventive health practices, [137-140] in compliance with medical regimens, [141-143] and in risk-reduction behavior (screening tests, smoking, weight control, diet, etc.). [142-145] The overlap among these behavioral categories is part of the problem but the lack of agreement on measures of behavior within categories is more than a classification problem.

Behavioral outcomes can be measured against previous behavior as well as absolute standards. Improvement can thus be a success measure; the standard becomes the level of improvement specified.

Measuring manpower implications: A major evaluation issue relates to the manpower implications of self-care programs. Self-care programs have as a principal objective the assumption of provider functions by consumers. Elsewhere in this paper we have listed such functions as cervical examination, throat culture, hyposensitization injections, and blood pressure reading as examples of traditional provider activities which consumers are being taught to perform for themselves. An important question for such programs thus becomes, can substitution of consumer for provider manpower occur in a manner significant enough to demonstrate reduced provider manpower needs? What types of providers are most likely to be "replaced" by activated consumers—physicians, nurses, paramedics, lab technicians, or others? How do the provider manpower reductions that constitute one theoretical benefit of self-care programs balance against the educational manpower needed to teach consumers effective self-care? How much provider time previously used in the treatment of conditions now treated by enlightened, self-caring consumers will be applied in the care of those whose problems or conditions demand the exercise of professional judgment and skills?

Cost-benefit analysis: An issue closely related to evaluation of the manpower implications of self-care programs is that of cost-benefit evaluation. On the most visible level, one can readily estimate the cost of an educational program on a total or per participant basis, incorporating direct program costs and the opportunity costs of the participants' time. The comparison of such costs to dollar estimates of program benefits, however, is somewhat more complicated. One must first be able to measure program benefits accurately. The benefit most educational programs aim for is an appropriate improvement in participant health status, or alternatively, the prevention of further deterioration (i.e., stabilization). How one measures patient health status is a key issue here, as is the period of time over which it is measured. Furthermore, one needs to be able to link appropriate health status changes with measures of the patient's social productivity in order to derive estimates of the economic benefit gained from improved health status. If an educational program leads to better health for a patient through improved health behavior, which in turn leads to fewer sick days off from work per year and two additional years of life in which the patient works instead of retiring for health reasons, one can begin to measure the economic benefit of the program in terms of (1) sick days "saved," (2) years of work gained, and (3) reduced burden on social support programs for the elderly. Such measures need to be further augmented by estimates of the value of provider time freed for other purposes by patient self-care.

Needless to say, the identification, measurement, and quantification of programmatic benefits in self-care is extremely difficult in itself, and needs to focus on both the patient and the provider. Placing an economic value on program benefits is equally difficult, involving issues of valuation (social discount rates, future dollars, specification of a "stream" of benefits over time, etc.) that often became very complicated. It is not our

intention to discuss such methodologic issues here. They have, in fact, been extensively treated elsewhere, in the growing literature on cost-benefit analysis for public programs. Rather, we hope by this discussion to stimulate thinking on the need in this area, as in other program areas, for careful evaluation of program benefits against program costs.

Measuring the limits of self-care: Another research issue in self-care is investigation of the extent to which self-care can really be undertaken. We know, for example, that diabetic patients have for years self-administered their insulin injections, and that this type of self-care has become, in fact, accepted patient care. At the other extreme, we can probably not ever expect a consumer to perform an appendectomy or any other surgery on members of his family. Somewhere in between the uncomplicated chronic care functions and the performance of major surgery lies the upper limits of patient self-care. Which clinical functions can consumers really perform for themselves? How reliable will consumers be relative to trained professionals? Ten years ago, cervical self-examination would probably have been considered a health-endangering practice; today, its reliability is being tested by such groups as the women's community health center described elsewhere in this paper. The extent to which consumers can truly become their own physicians has not yet been determined. Can consumers be trained to decide systematically, and in non-trivial situations, when to seek professional attention and when to care for themselves? The state of the art of self-care is continually expanding; research is now needed to probe its ultimate limits.

Measuring the utility of consumer algorithms: A more concrete research issue involves evaluation of the utility of patient decision checklists or algorithms in self-care. Can such checklists be reliably written by providers and uniformly applied by consumers in their own care? Answers to this question will help determine whether simplified medical "textbooks" and decision trees for patients can successfully be integrated into the nation's health care system.

Measuring the applicability of self-care education to various population groups: A legitimate research question to address is the comparative success of self-care education in different population groups. Can technical information on self-care be transferred to or absorbed by all population groups with the same ease? Some programs, for example, have been aimed primarily at middle class, sophisticated, educated population groups. Can they be equally well applied to lower socioeconomic groups, or in rural areas? A need exists for demonstration of self-care programs under various population circumstances, and for comparative evaluation of program results.

The need for standardized evaluation measures: The major obstacle to advancing the scientific base of health education practice in self-care programs is clearly the paucity of standardized measures of both input and outcome variables. This precludes the comparison of findings between studies and limits the generalizability of results. The scientific and professional literature related to health education is mushrooming in both the behavioral science and the health science journals, but it lacks the cumulative quality essential to the codification of knowledge and the development of policy that will have a coherent theoretical base. These observations lead to a major recommendation for governmental action to encourage methodological research on the measurement of self-care variables and the standardization of instruments to improve the comparability of findings from various self-care studies. A related recommendation should be to increase support for replicative studies. Most grants and contracts have been for isolated, ad hoc studies, rather than for evaluative research programs in which the same educational strategies are retested in different settings, or with carefully controlled variations to assess the cost-effectiveness of different methods or combinations of methods.

A case study

Studies reviewed earlier have established the efficacy of group discussion as a powerful educational method to improve preventive health practices and to improve patient compliance with medical regimens. The following case study is presented as an example of the potential of self-care education to improve appropriate utilization of health services and facilities.[123] Specifically, it illustrates the efficacy of group discussion as an educational strategy with chronic, but ambulatory asthmatic patients, to reduce their dependence on emergency department facilities by increasing their self-confidence, ability and commitment to cope with mild symptoms.

Rationale for the asthma education program: The design of the educational approach to asthmatics for this pilot study was based on four behavioral assumptions or propositions derived from experience with asthmatics:

1. Many asthmatics are frightened by their disease. The fear of not being able to breathe during the onset of asthmatic symptoms increases the severity of the attack and compels the patient to seek relief at the nearest emergency room.
2. The asthmatic assumes, probably correctly, that others who have the same disease can most fully understand this fear and the problems of coping with symptoms.
3. Therefore, in order both to prevent the anx-

iety associated with asthma symptoms and to increase the asthmatic's confidence in coping with the symptoms of an attack, asthmatics would benefit most from talking with each other under controlled circumstances.

4. The limits of control exercised by the professional in the group discussions among asthmatics should be:
   (a) to prevent them from arriving at a conclusion that asthma is unmanageable,
   (b) to provide desired technical information, upon request, about the best methods of managing symptoms, and
   (c) to support or encourage expressions of confidence in correct self-management of asthma.

It should be emphasized that an educational program based on this approach need not explicitly discourage the use of the hospital emergency department. The focus is on preventive measures and the management of early symptoms.

Study population: Patients were selected for this study who had come to the Johns Hopkins Hospital Emergency Room between May 28 and June 29, 1971, were between 15 and 45 years of age, and lived in either the hospital postal zone or one of the four surrounding postal zones. They had presented as asthematics in distress, as determined by the physician who entered the diagnosis of asthma or bronchial asthma, and who recorded administering medication to the patient while in the emergency room. The patients did not have lung tumors, chronic bronchitis, tuberculosis, or heart failure, as determined by review of emergency room patient records, and confirmed by patient interview. Patients meeting these criteria were selected from the emergency room billing records and randomly distributed between two patient groups, experimental and control, 29 in each group.

Letters of explanation were sent to those selected for the study, and all were visited at their homes to gain their cooperation and to distribute diaries for recording symptom levels. The control group was asked to fill out the symptom diary each day, so the investigators could study asthma by observing how they were feeling, whether they were using medicines, and if they had to use medical services. The experimental group was asked to fill out the diary for the same reasons, and was also asked to attend one evening group meeting with other neighborhood asthmatics to discuss and to learn from each other about the management of asthma. Patients in neither group knew they were being compared with other patients.

Educational program: In five group meetings, each with four to six different patients (each patient attending one meeting), a medical student conducted group discussions with emphasis on factors contributing to asthma which can be altered by patient behavior. Four areas were considered: one, life style, with attention to smoking, obesity, interpersonal relations, tension, emotional stress, and fatigue; two, allergens in the environment, and measures which can be taken to eliminate them; three, general health measures, including maintenance of good physical condition, avoidance of colds and respiratory infections as well as prompt attention to incipient colds, avoidance of climatic extremes, proper dress, and rest; and four, use of drugs, prophylactically and in an attack. Appropriate patient behavior in relation to these areas was expected to decrease the severity of symptoms and the necessity of resorting to the hospital emergency room in response to symptoms.

In the group meetings, the discussion leader, a third-year medical student, provided a comfortable setting, tried to maintain a nonthreatening group climate, and provided minimal but essential direction as the group members addressed their most pressing concerns, anxieties and questions about their asthma and its management. Effort was made by the discussion leader to initiate a group-decision process in which the group would agree on particularly effective means to manage asthma. Emphasis was placed on the early recognition of an attack, and the importance of rest and prompt medication to ameliorate it. The consequences of running out of medicine were also stressed. The five meetings, one for each group of 4 to 6 experimental subjects and lasting between 75 and 90 minutes, took place in the evening in classrooms of the Johns Hopkins University School of Hygiene and Public Health.

Evaluation of the patient education program: To evaluate the effectiveness of the group discussion sessions, three sources of data were used: symptom diaries, interviews and hospital records. The patients in the group discussions (experimental group) maintained daily symptom diaries which could be compared with identical symptom diaries kept by the patients in the control group. All patients rated the severity of various symptoms, including chest tightness and breathlessness, wheezing, cough, and quantity and color of sputum. The symptom diary had the advantage of having been used previously to evaluate a new drug for asthma in a recently published study.[17] Patients were also asked to record for five weeks their use of medicine and visits for care of asthma to the emergency room, to their local physician, or any other source of care. The symptom diaries were collected at intervals of one to one and one-half weeks, with the majority of study participants having one to two weeks of practice filling in the diaries before they began keeping diaries used for evaluation. During visits to pick up the diaries, the investigator interviewed patients in both groups to

determine age, past sources of care, duration of asthma, years of schooling, and use of Medicaid. Emergency room utilization was monitored for four months (July 19 to November 19, 1971) after the educational sessions by checking the daily emergency room billing records for visits for asthmatic treatment by patients in both study groups.

Results: Of the 58 patients randomly allocated to the experimental and control groups, data were collected from 26 in the experimental group (two had incorrect addresses listed and could not be located; one could not be contacted more than one time) and 26 in the control group (one moved without a forwarding address; one could not be contacted after several initial visits; one was eliminated because she was the mother of another woman in the experimental group). In the experimental group (n = 26) there were eight black men, seventeen black women, no white men, and one white woman. In the control group (n = 26) there were nine black men, fifteen black women, one white man, and one white woman. There were no significant differences in the ages, educational levels or duration of asthma between the experimental and control groups. Approximately two-thirds of both groups were eligible for and used Medicaid. Only two patients in each group indicated upon questioning that they had used other than Johns Hopkins Hospital emergency room for treatment of an asthma attack in the previous year.

Symptom levels: The symptom diaries yielded internally consistent data, although a few patients had some difficulty learning how to fill in their diary. In all cases, a non-judgmental clarification or explanation overcame the difficulties. Diaries were scored for symptom levels according to the methods of Chen and Associates.[146]

The symptom-level data for both the experimental and control groups during the three weeks after the educational sessions (July 19 to August 9, 1971) are presented elsewhere.[123] The control group mean symptom levels for chest tightness and breathlessness and wheezing (38.8 and 35.5) were higher than the corresponding means for the experimental group (31.9 and 26.8). The control group, however, had lower mean symptom levels for cough and sputum color and sputum amount (74.4) than the experimental group (84.7). When all the symptom level data were totalled, the mean for the experimental group (143.5) was lower than that of the control group (150.2). None of these differences, however, was sufficient to achieve statistical significance at a probability of .05 or lower.

Emergency room utilization: Cumulative statistics on the emergency room utilization by the experimental and control groups during the four months after the group discussion sessions (July 19 to November 19,1971) are presented in Figures 1 and 2. These data are based on hospital records rather than verbal reports of the subjects.

Figure 1 illustrates the cumulative number of different asthmatic patients returning to the emergency room for treatment of their asthma. In the first five weeks, nine different patients in the control group went to the emergency room for treatment, while two different patients in the experimental group visited the emergency room. This difference is statistically significant at $p < .05$ ($X^2 = 4.15$). During the subsequent twelve and one-half weeks this trend continued, with more different individuals in the control group than in

Figure 1

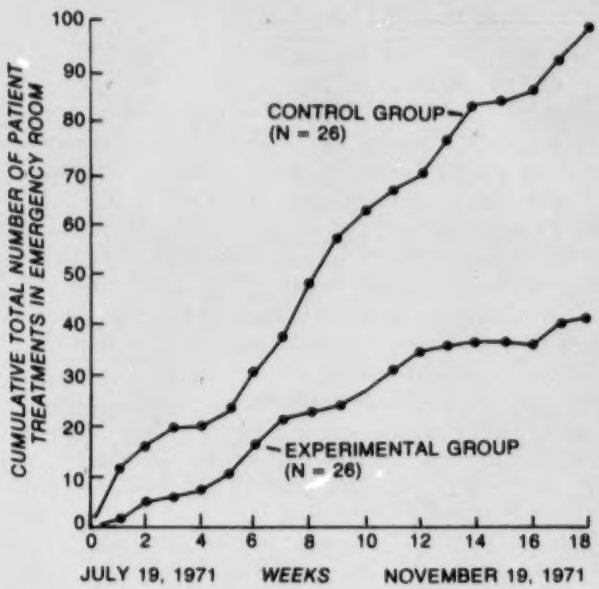
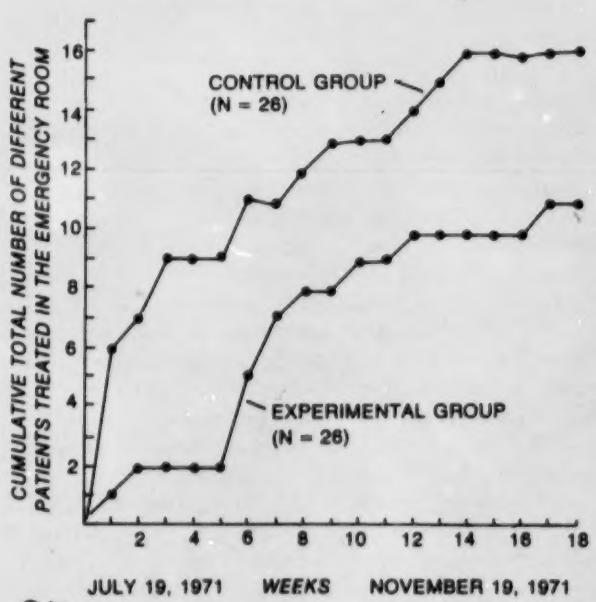


Figure 2



the experimental group treated for asthma in the emergency room.

Figure 2 illustrates the cumulative total number of visits to the emergency room for asthma treatment by the experimental and control group from July 19 to November 19, 1971. The cumulative total for the control group was at least two times that of the experimental group at all but one of seventeen weekly intervals, with the absolute difference in the number of visits between the experimental and control groups increasing from 13 visits at five weeks, to 36 visits at ten weeks, to 47 visits at fifteen weeks, and to 55 visits at nearly 18 weeks.

At the end of four months this reduced emergency room utilization, assuming a cost of $20 per emergency room visit, represents a $1,100 reduction in the cost of care for the experimental group.

Discussion: If the significant differences between experimental and control groups can be attributed to the effectiveness of the group discussion technique, then the value of mutual teaching by asthmatics of each other, of shared insights and feelings, and the value of group consensus regarding the importance of various means of managing asthma, are confirmed as important educational variables. These were distinctive features of the group discussions conducted with the experimental group. A conscious attempt was made not to influence attitudes or behavior during other phases of the study. During visits to collect diaries, the investigator was friendly with both groups, but attempted to provide no educational information, except to answer occasional questions as briefly as possible. In large part, the patients who asked questions received confirmation of their present practices from the investigator. It is not likely that answering questions biased results in favor of the educated group, for the majority of time discussing problems was spent with patients in the control group.

The important result of this study is the decreased emergency room utilization by the group discussion participants as contrasted with the control group. Without specifically discouraging the use of the emergency room, significantly smaller numbers of asthmatics in the experimental group were treated in the emergency room for at least five weeks after the educational session. At the end of the four months, 16 of 26 control-group members had been treated in the emergency room, compared with only 9 to 26 patients in the experimental group. One would expect on the basis of the previous experience of these asthmatics, that at the end of an extended period of time a high proportion of both groups would have returned to the emergency room. A difference, however, persists for the four-month period of this study. The potential of periodic educational sessions to maintain a disparity for a longer period of time should be considered. Of greater concern from a cost-benefit standpoint is the effect not on number of patients but on the cumulative total number of *visits* to the emergency room for asthma treatment. The control group during the four months of this study had at least twice as many visits as the experimental group at all but the seventh week when the ratio was only slightly less than 2 to 1. The absolute difference in the number of visits between the experimental and control groups increased from 13 visits at 5 weeks, to 55 visits at 4 months.

The most conservative assumption one might make in extrapolating from these results would be that the difference (the reduction in emergency room visits) disappears after four months. In fact, the lines in Figure 2 appear to be diverging rather than converging, but a minimal estimate of impact is possible without making assumptions beyond the existing data. Taking the reduction of 55 visits for 26 patients, or approximately 2 visits per patient, as the most that should be expected of a single educational program, and 5 patients as the optimal number for each group discussion, some specific cost-benefit ratios can be derived and generalized.

An emergency room visit at the time cost $20. Whether this amount was charged to the patient, to Medicaid, or to another insurance carrier, each patient visit to the hospital emergency room costs the medical care system an average of approximately $20. The educational program, consisting of one group discussion-decision meeting for at least five patients, results in at least ten visits fewer than would be expected of the same asthmatic patients receiving the standard emergency-room treatment of minimal education. Thus a savings of $200 in return visits accrues for each educational session. At a maximum cost of $40 per discussion session, the cost/benefit ratio would be at least 1 : 5.

All of the above assumptions, however, are conservative. It is likely that the impact of the program on the continued reduction of emergency room visits does *not* disappear after four months. It appears, in fact, that the early success of experimental patients in coping with their symptoms reinforces their confidence and further reduces their need to depend on the hospital emergency room for help. The number of patients that can be adequately educated in a discussion session may be as many as ten or fifteen rather than only five. Lay volunteers with minimal training may be as effective as a professional in leading the discussion groups, thus reducing the cost component. The $20 savings per emergency visit prevented does not take into account the associated savings to the patient of transportation to the hospital, time lost from work, and the general benefits of security and comfort in being able to cope with symptoms and to avoid severe attacks.

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List of conference participants

Dr. Gerald Rosenthal
Director, National Center for Health Services Research
HRA/DHEW

Dr. George A. Silver
Yale University School of Medicine

Dr. Lawrence W. Green
School of Hygiene and Public Health
The Johns Hopkins University

Dr. Michael Samuels
Bolinas, California

Dr. Mary Ann Lewis
Center for Health
University of California, Los Angeles

Dr. Keith Sehnert
Georgetown University

Dr. Ronald M. Andersen
Center for Health Administration Studies
University of Chicago

Ms. Gretchen V. Fleming
Center for Health Administration Studies
University of Chicago

Dr. Eva J Salber
Department of Community Health Sciences
Duke University Medical Center

Dr. Alfred Katz
School of Public Health
University of California

Ms. Sallie Adams
United States Senate Staff
Washington, D.C.

Dr. Lowell Levin
Yale University School of Medicine

Dr. Lee Sechrest
Department of Psychology
Florida State University

Professor Reginald Wells
SUNY at Stoneybrook

Dr. Jan Howard
Department of Anthropology/Sociology
Virginia Commonwealth University

Mr. Edward Roccella
The University of Michigan Medical School
Ann Arbor, Michigan

Mr. Maurice Glatzer
Bureau of Health Education, CDC, DHEW

Mrs. Mona Mitnick
Office of the Assistant Secretary for Planning and Evaluation/Health
DHEW

Mr. Edgar Le Roy Ross
DHEW, Region X
Seattle, Washington

Mr. Sherman R. Williams
Health Services Research and Development Center
The Johns Hopkins University

Mr. Dohn Rushing
Social Analysis Branch
Division of Health Services Research and Analysis, NCHSR

Dr. Jerry Weston
Assistant to the Director
DHSRA, NCHSR

Mr. William Lohr
Health Services Research Methods Branch
DHSRA, NCHSR

Mr. John Gallicchio
Social Analysis Branch
DHSRA, NCHSR

Mr. Archer Copley
Acting Director
DHSRA, NCHSR

Mr. Franklin B. Caffee
Acting Chief, Social Analysis Branch
DHSRA, NCHSR

Mr. Gerald Sparer
Acting Director
Division of Health Systems Design and Development and Evaluation, NCHSR

Dr. Robert Thorner
Division of Health Systems Design and Development, NCHSR

Ms. Elinor Walker
DHSDD, NCHSR

Mr. James R. Ullom
DHSDD, NCHSR

Mrs. Edith G. Robins
Division of Long Term Care, NCHSR

Dr. Kathleen Ittig
Staff Assistant for Consumer Affairs, NCHSR

Mrs. Bertha D. Atelsek
Director, Division of Health Services Evaluation, NCHSR

Dr. Betty Lockett
Bureau of Health Manpower, HRA

38 Ms. Patricia Shonubi
Bureau of Health Manpower, HRA

Mr. Lionel Fernandez
Chief, Program Development Branch
Office of Health Resources Opportunity, HRA

Invited, but unable to attend:

Mr. Rudy Salinas
Community Health Foundation
Los Angeles, California

Dr. Vincente Navarro
School of Hygiene and Public Health
The Johns Hopkins University

Dr. Howard Kalmer
Health Services Research and Development Center
The Johns Hopkins University

Dr. John Clark
Deputy Director
DHSRA, NCHSR

Mrs. Bernice Harper
Director
Division of Long Term Care, NCHSR

Mr. Daniel Zwick, Director
Office of Program Evaluation and Legislation
Health Resources Administration, USPHS

Ms. Wilma Dean Henry
Bureau of Health Education
Center for Disease Control, USPHS

Dr. David Kindig, Deputy Director
Bureau of Health Manpower, HRA, USPHS

Dr. Sidney Wolfe, Director
Washington Health Research Group

Dr. Irwin M. Rosenstock
School of Public Health
University of Michigan

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15. Supplementary Notes

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16. Abstracts Consumer self-care in health is a growing movement wherein lay persons increasingly function for themselves to prevent, detect, and treat health problems, and promote good health in a manner which supplements or substitutes for professional services. The movement can be traced to social and health legislation of the 1960s, changes in nursing theory, and the growth of self-help groups (also the more recent Feminist movement, and the growth of women's health centers and feminist therapy collectives have been influential in the popularization of self-care in health). Conferees have recommended a broad range of new research on the topic: a survey of consumer and health care provider attitudes and practices regarding more consumer involvement in the health care process; and the demonstration of new self-care theory and the evaluation of existing self-care programs and theory in terms of costs, efficiency, and satisfaction. The conferees also discussed ethical issues regarding research risks, the quality of self-care, and "at-risk" populations. Appended are four papers describing existing programs, the history and logic of the movement, and inferences concerning the consumer's desire for increased self-care.

17. ~~Key Words and Document Analysis - 17a. Descriptors~~ No. 16. Abstract (cont.)

17b. Identifiers/Open-Ended Terms

Health services research
Self-Care conference
Consumer self-care

17c. COSATI Field/Group

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